Depression in Internet and Face-to-Face Cancer Support Groups: A Pilot Study

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Purpose/Objectives: To examine depression in Internet cancer support groups as compared to traditional (face-to-face) cancer support groups and to explore the relationship between Internet use and levels of depression.

Design: Exploratory, descriptive.

Setting: Traditional (face-to-face) and Internet cancer support groups.

Sample: Convenience sample of 40 patients with cancer, 14 from traditional face-to-face groups and 26 from an Internet support group, with different cancer diagnoses.

Methods: Traditional paper or Internet surveys consisting of an investigator-developed questionnaire including demographic information, brief medical history, support group history, and the Center for Epidemiologic Studies Depression Scale (CES-D).

Main Research Variable: Depression scores on the CES-D.

Findings: Participants in the face-to-face groups were 100% male. The online group was 56% male and 44% female. Groups did not differ significantly by income, health insurance status, or days since initial diagnosis. Groups differed significantly on level of depression. The traditional (face-to-face) group had a CES-D mean score of 1.86 (SD = 2.69), and the online group had a mean score of 29.27 (SD = 11.89, $p < 0.000$). A comparison of CES-D scores of men in the face-to-face and Internet groups revealed that they differed significantly on level of depression. Men in the traditional group had a mean score of 1.86 (SD = 2.69), and men in the online group had a mean score of 27.42 (SD = 112.69, $p < 0.000$).

Conclusions: These data suggest that more depressed patients with cancer use Internet support groups instead of face-to-face support. Before online interventions can be implemented effectively, their efficacy needs to be evaluated.

Implications for Nursing: Patients with cancer are at increased risk for developing depression. This should be a consideration during nursing assessments. Traditional cancer support groups can help people cope with their cancer, but the efficacy of Internet cancer support groups in providing psychoeducation and psychotherapeutic intervention remains to be proven.

Key Points . . .

- A scarcity of research is available to support the efficacy of Internet support groups in achieving positive coping outcomes and reducing depression.
- The vast majority (92%) of those in the Internet group suffered from major depressive disorders, as compared to none in the face-to-face group.
- The data, on the surface, provide credence for the notion that the Internet as support may be related to depression in patients with cancer.

Almost 1.29 million people will be diagnosed with cancer in the United States in 2002, and 555,500 will die of the disease (Jemal, Thomas, Murray, & Thun, 2002). The psychological effects of cancer are well documented. A diagnosis of cancer may initiate a period of crisis accompanied by anxiety and fear. Spiegel and Classen (2000) indicated that a cancer diagnosis fostered great uncertainty and unleashed strong intrapsychic and interpersonal forces. Patients with cancer often feel anger, emotional distress, uncertainty about the future, and depression and have psychosexual concerns (Bottomley, 1997; Chernecky, 1999; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Galloway & Graydon, 1996; Gaston-Johansson, Ohly, Fall-Dickson, Nanda, & Kennedy, 1999; Zabalegui, 1999).

Nearly 50% of people receiving treatment for a malignancy will experience cancer-related depression (Carroll, Kathol, Noyes, Walk, & Clamon, 1993; Derogatis et al., 1983; De Walden-Galuszko, 1996; Leopold et al., 1998). Thus, this is a

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significant problem for patients with cancer. Twenty-five percent of patients with cancer may be suffering from depression at diagnosis (Hann, Winter, & Jacobsen, 1999; Lovejoy, Tabor, & Deloney, 2000; Mermelstein & Lesko, 1992). In a study of 809 women with cancer, Carroll et al. found that almost 50% exhibited symptoms related to depression and anxiety. Other research indicates that depression rates increased when patients had recurrent or metastatic disease, were within one month of diagnosis, or were in pain (Aasa, Fossa, Dahl, & Moe, 1997; Breitbart, 1995; Massie & Holland, 1990). Newport and Nemeroff (1999) summarized by tumor site the prevalence of major depressive disorders in patients with cancer. They reported that malignancies of the pancreas, oropharynx, breast, and colon were associated with higher depression rates than other sites.

Pasacreta (1997) determined that women with breast cancer who were depressed reported more physical symptoms and more impaired functioning than women who were not depressed. Depression in patients with cancer has been reported to increase length of hospitalization, interfere with treatment, and adversely affect quality of life (Gaston-Johansson et al., 1999; Sellick & Crooks, 1999). Watson, Haviland, Greer, Davidson, and Bliss (1999) found high depression scores were linked to survival rates in women with breast cancer. The investigators reported that women age 18–75 with early stage breast cancer and high depression scores had a significantly increased risk of death from all causes over a five-year period.

Adjuvant chemotherapy has been shown to improve both disease-free survival and overall survival in patients with early-stage breast cancer. Colleoni et al. (2000) reported that depressed women were less likely to accept adjuvant therapy as part of their treatment for breast cancer. The researchers stressed the importance of treating depression as a means to increase acceptance of adjuvant chemotherapy and possibly improve prognosis.

Advances in technology (e.g., the Internet) may offer effective methods of providing psychoeducation and psychotherapeutic interventions to those not able or willing to receive help in more traditional face-to-face methods. Providing an evidentiary basis for use of these technologies is the overarching aim of this exploratory research. The specific purposes of this pilot study were to examine depression in Internet cancer support groups as compared to traditional (face-to-face) cancer support groups and to explore the relationship between Internet use and levels of depression.

Cancer Support Groups

The role of support groups in helping people cope with cancer is well documented (Cella & Yellen, 1993; Fobair, 1997; Pillon & Joannides, 1991). Support groups offer information on cancer and its treatment, help members cope with illness, provide emotional support, and facilitate psychosocial adjustment (Cella & Yellen; Fobair; Grassman, 1993). Leavitt, Lamb, and Voss (1996) argued that physicians did not adequately meet the informational needs of patients who were being treated for brain tumors. The authors suggested that patients with cancer were better able to help other people with cancer meet the physical and emotional problems associated with their disease. According to Hurt, McQuellen, and Barrett (1994), patients with cancer often felt anxious and helpless after treatment and when medical surveillance was not as intense. Wellisch (1993) believed that social support after treatment was essential in helping patients cope with their disease.

Samarel et al. (1998) studied 70 women with early-stage breast cancer who attended a support group for eight weeks. The women reported that the group helped them feel less alone, gain helpful information, and take advantage of opportunities to verbalize their feelings. These findings were supported by McLeod's (1999) study of women with secondary breast cancer. The author reported that support group members were less isolated and better able to communicate what they felt about their cancer experience. Coward (1998) designed an eight-week cancer support group for women with breast cancer. The results indicated that functional performance, mood state, and satisfaction improved significantly by the end of the study. In another study, 56 women with breast cancer were evaluated for coping patterns and side effects of treatment (Shapiro et al., 1997). The authors suggested that the women's willingness to discuss and think about their illness was an important factor for optimal coping.

Stanton et al. (2000) explored emotional expressive coping in 92 women with stage I or II breast cancer 20 weeks after they completed primary treatment. Women who used emotional expression as a coping mechanism reported decreased distress and needed fewer medical appointments to address cancer-related morbidity. Spiegel, Bloom, Kraemer, and Gottheil (1989) studied the effect of psychosocial treatment and survival time in women with metastatic breast cancer. A one-year intervention consisting of weekly support-group therapy and self-hypnosis for pain was conducted. Women were assigned randomly to either an intervention group (i.e., group support and self-hypnosis) or a control group (i.e., treatment as usual). Ten-year follow-up of the participants revealed that the women in the treatment group survived almost 18 months longer than those in the treatment-as-usual group (36.6 months versus 18.9 months). Kogan, Biswas, Pearl, Carlson, and Spiegel (1997) conducted a follow-up study to determine whether the survival effect in these women could be explained by differences in medical treatment. Researchers reviewed the medical charts of 61 women and the death certificates of 83 women and concluded that survival differences were independent of differences in medical treatment.

Although much of the work regarding cancer support groups has been conducted on women with cancer, some studies have included men. Fife, Kennedy, and Robinson (1994) conducted a study of 125 men and 208 women that investigated the clinical implications of gender and adjustment to cancer. Results indicated that women used coping strategies more frequently and more effectively than men and men were less likely to construct a positive meaning about their cancer. The authors speculated that women focused more on altering their emotional responses to cancer, whereas men were more likely to concentrate on solving the problem of having a malignancy.

Curn (1993) started a face-to-face support group for men with prostate cancer. Initially, the author believed that men would not express their feelings in a group. However, she found that the men freely discussed the anger and frustrations associated with their illness. In addition, the group provided emotional support, suggestions, and advice to members. Gray, Fitch, Davis, and Phillips (1997) interviewed men in a prostate cancer group and noted that the primary reason for joining was a need for information. Coreil and Behal (1999) surveyed face-to-face prostate cancer groups in Florida. They reported that most group members (83%) valued information and education about prostate cancer and

only 5% percent valued receiving social and emotional support or sharing experiences with others. Bastecky, Tondlova, Vesela, Brizekova, and Boleloucky (1996) studied individuals with breast and gastrointestinal cancers. They found no differences in psychopathology between the two groups. However, only 12 of 107 subjects were male.

Online Support Groups

Historically, support groups were designed to meet the needs of patients with cancer in a community setting (e.g., hospital, church, clinic) and were run by a professional facilitator. In the past decade, online support groups have become a popular alternative to traditional groups. Similar to traditional groups, Internet groups offer social support, information, shared experience, positive role models, empowerment, professional support, and patient advocacy (Madara & White, 1997). Internet support groups may be resistant to some of the pitfalls of traditional groups, such as the ebb and flow of attendance and inconvenient meeting times (Finfgeld, 2000; Klemm, Reppert, & Visich, 1998; Oravec, 2000). People with cancer use online support groups because they offer 24-hour access, at-home availability, anonymity, information, support, and convenience (Fernsler & Manchester, 1997; Klemm, Hurst, Dearholt, & Trone, 1999; Sharf, 1997). Madara and White described online communication as an "equalizer," lacking the visual distractions of age, gender, dress, and social status seen in traditional support groups.

Several disadvantages to online support groups have been noted. These include the lack of a professional facilitator, no visual cues or face-to-face interaction, posting of incorrect information, and a risk of social isolation. Finfgeld (2000) indicated that natural leaders emerged on the Internet groups even without a trained facilitator. Klemm et al. (1998) noted that members of the group quickly corrected inaccurate information posted online.

As early as 1995, Fawcett and Buhle (1995) suggested that the Internet was a viable method by which to collect data. Fernsler and Manchester (1997) queried users of a computer-based cancer support network and found that individuals joined to learn from others who had similar experiences, garner information, encourage others, and obtain psychological support.

Thomas, Leeseberg-Stamler, Lafreniere, and Dumala (2000) described the use of the Internet to survey an international population of 593 women about breast cancer education and screening. Women from Canada, the United States, Australia, Brazil, the Netherlands, and the United Kingdom participated in the study. The researchers concluded that the Internet provided a cost-effective way to obtain, manage, and analyze research data.

Much of the research on computer-based groups has focused on women with breast cancer. Gustafson et al. (1993) developed a computer-based support system to help women with breast cancer cope with their disease. The Comprehensive Health Enhancement Support System (CHESS) allowed users to have questions answered, obtain help and support, tell their personal stories, ask an expert, and participate in discussion groups. Age and educational differences did not affect the women's use of CHESS. Older and less-educated women used the system as frequently as younger and more-educated women.

McTavish et al. (1995) investigated an underserved population of patients with breast cancer via CHESS. A pilot study included eight African American women from poor neighborhoods. The researchers found that 55% of total time use in the group was devoted to social support issues, whereas 41% focused on information seeking and giving. In addition to the psychosocial support the group offered, several barriers to participation (e.g., transportation, child care) were solved by the home-based computer system. In 1996, Weinberg, Schmale, Uken, and Wessel reported on their use of a computer-mediated support group for women with breast cancer. Results suggested that the computer-mediated group provided the same therapeutic benefits of traditional support groups while in the comfort of the home. Sharf (1997) discovered three dimensions in communication (exchange of information, social support, and empowerment) in a computer-based support group for women with breast cancer.

A few studies on Internet groups have included men. Klemm et al. (1998) identified eight response categories in 48 men and 46 women with colorectal cancer who belonged to an online support group. Information giving and seeking (25%) and personal opinions (22%) accounted for the highest percentages of the messages posted. Encouragement and support (17%) and personal experiences (16%) also were well represented. These four categories accounted for about 81% of all messages posted by group members. The remaining categories of thanks, humor, prayer, and miscellaneous made up almost 19% of responses. From this, the researchers concluded that the Internet support groups provided psychosocial support to patients with cancer and caretakers. A more recent study by Klemm et al. (1999) compared breast, prostate, and colorectal Internet support groups. The investigators sorted 1,541 messages into the eight categories described in their earlier study and found that men and women used the online groups differently. Men (n = 117) with prostate cancer most often posted information giving and seeking (36%) with information regarding personal experience (23%) second. These categories were reversed for the women (n = 126) in the breast cancer group (personal experience, 28%; information giving and seeking, 23%). About 22% of messages posted by the women in the breast cancer group offered encouragement and support, whereas only 8% of messages posted on the prostate cancer group site were placed in this category. When the messages for both the prostate and breast groups were considered together, about 83% of the messages posted were placed in the categories of information giving and seeking, encouragement and support, personal opinions, and personal experience.

Fernsler, Klemm, and Miller (1999) used the Internet to enlist 121 subjects (men = 68, women = 53) for a study investigating spiritual well-being and demands of illness in patients with colorectal cancer. The participants were from 25 states and six countries other than the United States. Results indicated that the greatest number of illness-related demands were present in the youngest group of patients (aged 26–45 years), those with limited activity, and those who reported a terminal stage of disease, regardless of gender.

Kraut et al. (1998) indicated that the amount of time spent on the Internet correlated positively with depression. The investigators tracked the Internet use of 169 participants from 93 households over a two-year period and found that depression rates and feelings of loneliness increased as time spent on the Internet increased. More recently, Nie and Lutz (2000) surveyed 4,113 American adults and found that people who spent more than five hours per week online spent less time

with family and friends. Social withdrawal, lack of direct interpersonal contact, and other reduction of interaction could be driving these findings. However, some people must reduce their social contact for health reasons. The availability of Internet communication seems to offer a wealth of potential for these individuals.

Research studies have shown that face-to-face support groups help decrease psychological symptoms, enhance functional performance, decrease depression, and prolong survival in patients with cancer. However, a scarcity of research is available to support the efficacy of Internet support groups in achieving positive coping outcomes and reducing depression.

Methods

Design and Sample

This exploratory descriptive study was comprised of a sample of 40 patients with cancer who participated in two support groups (i.e., face-to-face and Internet) selected by convenience. Fourteen members of traditional face-to-face support groups for patients with prostate cancer and 26 members of an Internet support group whose members had different cancer diagnoses participated. The selection of the face-to-face group was based on convenience and access; as such, local support groups were chosen. Selection of Internet discussion groups was determined by access and a brief monitoring period of traffic to ensure adequate volume. Initial consideration about group selection assumed that men, based on historic demographic data on Internet users, would overrepresent the Internet group. Thus, researchers reasoned the selection of a face-to-face group of patients with prostate cancer for the pilot would provide a pragmatic match. In fact, this was not born out in the sample.

Subjects were at least 21 years old, treated for cancer, and belonged to either a face-to-face or Internet support group. After receiving institutional approval for the protection of human subjects, face-to-face participants were accessed via local support groups. The primary investigator attended two face-to-face meetings (with permission of the facilitator), explained the study, and asked for participants. The investigator asked potential subjects to sign a written consent form and return the study instruments to the group facilitator at the end of the meeting. The facilitator then returned the instruments to the primary investigator.

Once permission from the Internet support group "owner" was obtained, a "call for participants" was posted for potential online subjects. If subjects wanted to participate or find out more about the study, investigators directed them to a Web page designed for purposes of the study. The investigators posted an electronic consent form along with directions on how to complete the study questionnaires online. Return of the survey by electronic mail was considered to be consent. Study recruitment ran for approximately one month.

Instruments

The participants received one of two forms of the survey. The patients in the face-to-face group received a paper survey consisting of an investigator-developed questionnaire including demographic information, a brief medical history, support group history, and a depression measure. The Internet group subjects received a similar instrument with additional questions about Internet support group history. The Internet form was completed online using Perseus Survey Solutions for the Web 2.01 software. The software facilitates the development of a web-based survey and e-mails the responses to the research team.

Subjects were assessed for their level of depression using the **Center for Epidemiologic Studies Depression Scale (CES-D).** The CES-D is a 20-item, self-report scale developed by Radloff (1977) that has been widely used in the assessment of depression. Each item is given a rating of 0–3, with a potential range of 0–60 for the entire scale. Higher scores are associated with depression. The cutoff for the diagnosis of major depressive disorder on the CES-D is 16. The instrument is a reliable measure (" > 0.85) of depression (Hann et al., 1999; Radloff). In 1998, Beeber, Shea, and McCorkle supported the reliability and validity of the CES-D in measuring depression in 453 newly diagnosed patients with cancer.

Data Analysis

Investigators completed a descriptive statistics and normality screen to verify normality for the data. Contrasts between the two groups were determined using chi-square and independent group t tests. To examine the relationship between level of depression and time on the Internet, a Spearman correlation was used. This statistic was chosen because the pilot survey used ordinal ranges to determine the amount of Internet use.

Results

Forty patients with cancer participated. The sample contained 14 men from traditional face-to-face support groups for prostate cancer and 26 members of an Internet support group with different cancer diagnoses. All members (n = 14) of the traditional face-to-face group were male, whereas the online group was 56% (n = 14) male and 44% (n = 12) female. Eighty-three percent of the total sample (n = 33) were married, 10% (n = 4) were separated or divorced, and 7% (n = 3) were single or never married. The two groups did not differ by income, health insurance status, or mean number of days since initial diagnosis. No members of the traditional face-to-face group rated themselves as "terminal" compared to four in the online group. This difference was not significant.

The groups differed significantly by percent of patients receiving active treatment in the prior month (face-to-face: n = 2 [14%], Internet: n = 14 [54%]) (P^2 [1, n = 40] = 4.95, p < 0.026), mean number of months in a support group (face-to-face: 34.2 months, Internet group: 11.8 months) (t [35] = 3.282, p < 0.02), and level of depression (see Table 1). The traditional face-to-face group had a mean score of 1.86 (SD = 2.69) on the CES-D whereas the online group had a mean score of 29.27 (SD = 11.89) (t = –8.46, p < 0.000).

No significant difference occurred in the level of depression between men and women in the online group. Twelve of 14 men (86%) in the Internet group had mean scores on the CES-D above 16 (the cutoff score for major depressive disorder), while all the women (n = 12) in the online group had scores above 16. CES-D scores of the men in the Internet group (27.42 [SD = 12.69]) and men in the face-to-face group (1.86 [SD = 2.69]) were significantly different (t = –7.37, p < 0.000).

Table 1. Selected Characteristics of the Face-to-Face and Internet Cancer Support Groups

Characteristic	Face-to-Face (n = 14)	Internet (n = 26)	p
Gender			NS
• Male	14	14	
• Female	–	12	
Cancer type	Prostate	Mixed	NS
Mean days since diagnosis	1,386	1,123	NS
Undergoing active treatment in prior month	2	14	≤ 0.026
Number of months in support group	34.2	11.8	≤ 0.02
Depression scores[a]			≤ 0.000
• Scores	1.86	29.27	
• SD	2.69	11.89	

NS = not significant

[a] Cut-off score for major depressive disorder on Center for Epidemiologic Studies-Depression Scale is 16.

The scores indicated that the vast majority (92%) of those in the Internet group suffered from major depressive disorder as compared to none of the participants in the face-to-face group. Face-to-face group members reported that they did not belong to an Internet support group or spend time online. The Internet group averaged 2.6 hours (range = 1–7) in the online support group and 6.2 hours (range = 2–14) total time online each week.

Investigators completed further analysis of the Internet group to examine the Spearman correlation between total time on the Internet and level of depression. The correlation between these two variables approached significance ($r_s = –0.38$, $p = 0.064$). Of the individuals in the Internet support group who were depressed, those with the highest scores on the CES-D generally spent less time on the Internet than depressed individuals with lower scores on the CES-D.

Discussion

The data, on the surface, provide credence for the notion that the Internet as support may be related to depression in patients with cancer. Investigators noted clear differences in depression scores between those in the face-to-face group and those receiving support via the Internet. Although the Internet subjects reported the amount of time they spent online per week, researchers could not determine if the high depression rate of this group was related to the amount of time spent online or to other factors as yet unknown.

Newport and Nemeroff (1999) reported that people with pancreatic malignancies had the highest depression rates among patients with cancer, followed by malignancies of the oropharynx, breast, and colon. Depression rates in the Newport and Nemeroff study did not rise above 50%. None of the patients in the current study comparing face-to-face and Internet support groups had cancer of the pancreas, oropharynx, or breast; however, 92% of the online group had CES-D scores that indicated major depression. Fife et al. (1994) reported women with cancer had better coping skills than men. In the current study, women were expected to have had a lower depression rate than men. No significant differences were evident in CES-D scores when gender was considered. Eighty-six percent of the men and 100% of the women in the Internet group had CES-D scores indicating major depressive disorder.

Research studies have indicated that depression is a major problem for people receiving treatment for a malignancy (Derogatis et al., 1983; De Walden-Galuszko, 1996; Leopold et al., 1998). In the current study, half of the subjects in the Internet support group were receiving treatment at the time they participated. Even so, active treatment alone does not account for the high depression scores in these subjects. Colleoni et al. (2000) reported that depressed women were less likely to accept adjuvant chemotherapy, an integral part of the treatment for early-stage breast cancer. Possibly, treatment choices of the Internet respondents in the current study may be affected by their psychological state. Watson et al. (1999) reported that survival was reduced in women with breast cancer who were depressed. Possibly, the high depression rates reported by the Internet support group members in the current study will affect their survival, as well.

Kraut et al. (1998) indicated that people became more depressed as they spent more time online. The subjects in the Kraut et al. study did not have cancer. Given that patients with cancer have higher depression rates than the general population, perhaps spending time online is associated with even greater depression rates. On the other hand, self-selection may have played a role in the findings of the current study. Subjects who were depressed may have been more inclined to participate in this study, therefore skewing the findings.

Secondary analysis of the online group suggests that among the patients who were depressed, less time spent online was associated with higher levels of depression. This is consistent with clinical experience. Those with severe levels of depression often have difficulty with simple activities of daily living. They may be less likely to use the Internet for support. Conversely, the argument exists that the difference between the face-to-face and Internet support groups is related to the depressive effects of social isolation associated with time on the Internet.

Limitations

This pilot study had a small sample size, which limits generalizing the results to the larger population. This sample of men and women could not be considered representative of all people who attend support groups. The findings in this study might be explained by variance between the types of cancer, gender, or the self-selection of subjects participating in both groups. Other factors that may have affected the results are the inherent biases found when groups lack randomization. Threats to the validity and reliability of the findings in this pilot study are apparent. Only men with prostate cancer were represented in the face-to-face support groups. Although the depression rate among these men was zero, these outcomes cannot be generalized to women or men with other types of cancers. In addition, it should not be assumed that the high depression rate found in the Internet support group is representative of other Internet groups.

Conclusions

Considering both the compelling natures of the data and the identified weaknesses, this study provides impetus for further exploration of the efficacy of Internet support. Ran-

domized clinical trials comparing face-to-face, Internet, and treatment as usual (i.e., no intervention) groups should be conducted to help determine the effectiveness of Internet support. The potential for providing life extension via an Internet format to patients unable to tolerate face-to-face group support has significant appeal. Research should explore potential risks to better understand the limitation of this treatment approach.

Implications for Nursing

Research has indicated that patients with cancer are at a higher risk for developing depression (Aasa et al., 1997; Breitbart, 1995; Hann et al., 1999; Newport & Nemeroff, 1999). This should be a consideration during initial and subsequent nursing assessments. Traditional support groups can help people with cancer function more effectively with their disease. Nurses should consider recommending face-to-face groups to help people cope with their illness because they have been shown to decrease depression and foster coping in patients with cancer. However, the efficacy of Internet cancer support groups in providing psychoeducation and psychotherapeutic interventions has not been proven. Although the Internet support groups may offer many benefits, nurses should be aware of the potential pitfalls and monitor their patients' responses accordingly.

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- About: Cancer Support Groups
  www.cancerlinksusa.com/support/
- Association of Online Cancer Resources, Inc.
  www.acor.org
- OncoChat
  www.oncochat.org/

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.