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Abstract

Cervical cancer screenings, colposcopy, and a diagnosis of human papillomavirus (HPV) increase anxiety in clients. Researchers have investigated several interventions to reduce emotional distress in clients, including disseminating informational leaflets and brochures, offering educational and counseling services, and hypnotherapy. There is insufficient evidence, however, for the effectiveness of informational leaflets in reducing anxiety and improving knowledge and client satisfaction. This article examines the utility of such an intervention and explores ones that may be more effective in reducing anxiety prior to, during, and after HPV and cervical cancer screening and management. Because HPV follow-up can involve several steps that take place over approximately two years, it is important to keep clients engaged in the system along the way. This article also examines if informational interventions increase client knowledge of cervical cancer and its cause, HPV and what impact this has on follow-up.

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Abstract

Cervical cancer screenings, colposcopy, and a diagnosis of human papillomavirus (HPV) increase anxiety in clients. Researchers have investigated several interventions to reduce emotional distress in clients, including disseminating informational leaflets and brochures, offering educational and counseling services, and hypnotherapy. There is insufficient evidence, however, for the effectiveness of informational leaflets in reducing anxiety and improving knowledge and client satisfaction. This article examines the utility of such an intervention and explores ones that may be more effective in reducing anxiety prior to, during, and after HPV and cervical cancer screening and management. Because HPV follow-up can involve several steps that take place over approximately two years, it is important to keep clients engaged in the system along the way. This article also examines if informational interventions increase client knowledge of cervical cancer and its cause, HPV and what impact this has on follow-up.

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Several studies have linked HPV diagnosis to feelings of shame, anxiety, depression, and isolation (Maggino et al., 2007). Additional layers of distress are added due to fear of pelvic and other gynecologic exams, transmitting the infection to sexual partners, and social stigma (Maggino et al., 2007). Additionally, because of the various levels of HPV diagnoses that may require anything from watchful management to invasive treatments, such as loop electrosurgical excisional procedure (commonly known as LEEP), the confusion over diagnosis also contributes to emotional distress (Daley et al., 2010). Not only does confusion lead to negative emotional response, it also may decrease follow-up rates (Daley et al., 2010). Factors as wide-ranging as baseline levels of anxiety prior to diagnosis, ethnicity, and smoking status all play a role in the presence of emotional distress following HPV diagnosis (Johnson, Sharp, Cotton, Harris, Gray, & Little, 2011). One study found that women who are single, have children, have high trait anxiety, and anticipate fear and pain prior to procedures are at greatest risk for distress due to colposcopy (Kola & Walsh, 2011).

Due to the high incidence and complexity of anxiety and emotional distress in response to HPV diagnosis, clinicians and researchers have investigated the most effective psychosocial interventions. One of the most commonly used interventions in the clinical

setting is informational written materials, such as brochures, leaflets, and posters. In fact, due to the fact that many clients may only receive written information from their clinician without any face-to-face discussion, it is critically important to study the impact of these materials on clients' lives. This article examines the effectiveness of this intervention in reducing anxiety and keeping clients engaged in the long follow-up process associated with HPV.

The evidence is mixed as to whether such materials increase knowledge about the medical aspects of HPV and decrease anxiety. A 2008 Australian study found that anxiety is increased in women with an HPV diagnosis when they receive less knowledge about HPV (Hall, Howard, & McCaffery, 2008). Several other studies, however, have found that informational interventions alone did not significantly decrease anxiety. One study even found that psychosexual problems actually increased with the dissemination of information leaflets prior to colposcopy (Howells et al., 1999).

Clients report wanting information about HPV but the ways in which information is presented often is problematic. For instance, written materials may overemphasize medical information and neglect the psychosocial impact of an HPV diagnosis (Hall et al., 2008). Additionally, most informational materials focus on treatment options despite the fact that most women with an abnormal Pap smear result will not require treatment, thus skewing the lived experience of most women with HPV (Hall et al., 2008). Finally,

most clients perform their own research about HPV online and clinicians need to be aware of the most accurate online resources so that they may refer clients to them (Perrin et al., 2006).

The Burden of HPV

There are more than 120 identified strains of HPV, approximately 40 of which can infect the genital tract of men and women (Association of Reproductive Health Professionals, 2009). As of 2012, the Centers for Disease Control and Prevention (CDC) estimates that nearly 20 million Americans are infected with HPV and 6 million new cases are diagnosed annually (CDC, 2012). Nearly 50% of all sexually active Americans have HPV infections (CDC, 2012). While HPV is most often transmitted through vaginal or anal intercourse, it also is transmitted by skin-to-skin contact therefore condoms do not offer complete protection from the infection (Association of Reproductive Health Professionals, 2009). Like all viral infections, there is no cure for HPV the most infections usually resolve without any intervention (American Society for Colposcopy and Cervical Pathology, 2012).

Nearly 100% of cervical cancer cases test positive for HPV (Saslow et al., 2012). Additionally, there is a strong association between HPV and cancers of the vagina, penis, vulva, anus, and oropharynx (Association of Reproductive Health Professionals, 2009). HPV 16 accounts for 55–60% of all cervical cancers, HPV 18 for an additional 10–15% cases, and 10 other HPV genotypes make up the remaining 25–35% of cervical cancer diagnoses (Saslow et al., 2012). It should be noted that types 6 and 11 are associated with condylomata acuminata, or external genital warts, but not cervical cancer (Association of Reproductive Health Professionals, 2009). HPV types 16 and 18 are considered high-risk due to their relationship to cervical cancer. In 2012, an estimated 12,170 cases of invasive cervical cancer were diagnosed and 4,220 women died of the disease (Saslow et al., 2012).

The major contributing factor to cervical cancer is inadequate or lack of screening (Saslow et al., 2012). Among those who are rarely or never screened in the U.S. are racial and ethnic minorities, lower socioeconomic status, being foreign-born and living in the U.S. for less than 10 years, and lack of access to health care and health care payment coverage (Saslow et al., 2012).

Although cervical cancer is now the 14th leading cause of cancer death in the United States, just 50 years ago it was the most frequent cause of cancer

death in women (Saslow et al., 2012) and continues to be the second most common cancer in women worldwide (World Health Organization, 2010). Increased cervical cancer screenings with Papanicolaou smears—commonly referred to as Pap testing—and technological improvements in screening methods have significantly reduced cervical cancer mortality (Saslow et al., 2012). In recent years, two HPV vaccines have been introduced. Released in 2006, Gardasil offers protection from HPV types 6, 11, 16 and 18 in females aged 9 to 26 and genital warts caused by types 6 and 11 in males aged 9 to 26 (Food and Drug Administration [FDA], 2011). Cervarix was released in 2009 and offers protection from HPV types 16 and 18 in females between the ages of 9 and 25 (FDA, 2011). Vaccination does not preclude the need for screening (Association of Reproductive Health Professionals, 2009).

HPV and cervical cancer are terms often used interchangeably and the general health care practitioner as well as clients may have difficulty distinguishing between various types of abnormal Pap smear results and cervical cancers. It is crucial that health care providers understand the differences and be able to clearly articulate them to clients. Cervical dysplasias as detected by cytology are as follows:

- Atypical squamous cells (ASC): This means that detected squamous cells do not appear normal but are not quite abnormal either. It includes two subcategories of ASC of undetermined significance (ASC-US) and ASC-cannot rule out high-grade (ASC-H). 50%-60% of women who receive this result are HPV negative and have no cervical pathology. ASC-H is a rarer finding, however, 60%-80% of women who receive this finding test positive for high-risk HPV types and the risk for more advanced cervical cancer is much higher than with ASC-US.
- Atypical glandular cells (AGC): This is a rare Pap smear finding that means detected glandular cells do not look either normal or abnormal. This finding has a greater risk of squamous and glandular precancer or cancer than any Pap smear finding except for high-grade squamous intraepithelial lesion (HSIL), which will be further discussed below.
- Low-grade squamous intraepithelial lesion (LSIL): In women under the age of 35, 83%-94% also test positive for HPV. 50% of women over

the age of 35 with LSIL will test positive for HPV, which suggests that the cervical changes in the other 50% are unrelated to HPV and may be due to hormonal changes due to aging. Across all age groups, 70% of women with LSIL will have vaginal or cervical cell changes due to HPV, though most of the changes are low-grade.

- High-grade squamous intraepithelial lesion (HSIL): Over 90% of women with HSIL will have cell changes due to high-risk HPV types. Cervical changes are often high-grade with this Pap smear interpretation.

- Cancer: Very rarely, a Pap smear can be suspicious for cancer.

(American Society for Colposcopy and Cervical Pathology, 2012)

The following are histological categories of cervical dysplasia, or cervical intraepithelial neoplasia (CIN):

- CIN I: mild dysplasia
- CIN II: moderate dysplasia confined to the basal 2/3 epithelium
- CIN III: Severe dysplasia that covers more than 2/3 of the epithelium and may involve full thickness. Also includes carcinoma in situ.

(MedlinePlus Medical Encyclopedia, 2012)

Most HPV infections are asymptomatic and become undetectable upon screening and testing within one to two years of initial diagnosis (Saslow et al., 2012). Current screening guidelines in the United States recommend that women begin cervical cancer screening with Pap tests at 21 years of age (Saslow et al., 2012). For women under the age of 30, annual screening leads to twice the number of colposcopies performed and offers no significant reduction in cancer incidence, therefore it is generally recommended that women be screened every three years (Saslow et al., 2012). For women between the ages of 30–64, cytology and HPV testing every five years is recommended (Saslow et al., 2012). Current guidelines recommend that screening be stopped at age 65 for women with adequate negative screening (defined as three consecutive negative Pap smears or two consecutive negative HPV tests) and no diagnosis of CIN2 or greater in the last 20 years (Saslow et al., 2012). Current studies on the effectiveness of testing for HPV in males are ongoing (Association of Reproductive Health Professionals, 2009)

Given HPV's transient nature, lack of symp-

toms and cure, and link to cancer, it is understandable that many patients and clients find screening and follow-up distressing. The anxiety present may impede initial screening and recommended follow-up. The fact that the infection can remain undetected and latent for years may increase uncertainty and anxiety (Rosen et al., 2010). Additionally, because HPV follow-up can take years for some clients, it is crucial that nurses and other health care providers attune themselves to their clients' psychosocial and informational needs by offering accurate information and, just as importantly, perspective.

Presentation of Empirical Evidence

How Demographics Impacts Information Dissemination

Although simulated laboratory experiments have found that people prefer to have information prior to a potentially stressful event, studies in non-laboratory settings that more closely reflect authentic clinical environments have found that people actually prefer to distract themselves from distressing events (Miller & Mangan, 1983). Additionally, one landmark study on the effect of informational leaflets on psychosocial responses to colposcopy found that patients who received limited information about the procedure experience less discomfort than those who received high levels of information about the procedure (Miller & Mangan, 1983). On the opposite end of the spectrum, when clients perceive the information given by their health provider as inadequate, this also increases anxiety scores (de Bie et al., 2011).

Informational leaflets regarding HPV can be classified into two main groups: those that encourage screening for HPV and cervical cancer and those that provide information on the medical implications of an abnormal Pap smear result (Hall et al., 2008). Materials that encourage screening often used alarmist language, such as "Don't delay—it could save your life!", which belies the fact that most HPV cases do not progress to cervical cancer (Hall et al., 2008) and can potentially increase anxiety in the reader. Conversely, brochures geared towards women who have already received abnormal screening results used calm, reassuring language and contained more information about the sequelae of HPV (Hall et al., 2008).

Creators of health-related information pamphlets often target each document to certain demographic groups. While the intention behind tailoring health information materials is inclusion, the outcome may be less than desired. In HPV leaflets targeted to

lesbian women, sexual practices were covered more frequently than in pamphlets directed at other groups (Hall et al., 2008). In HPV booklets directed towards older women, sexuality was discussed only within the context of heteronormative, monogamous marriage while materials directed towards women with disabilities ignored the issue of sexuality entirely (Hall et al., 2008). The assumptions made about each group determined the depth of information given and may have hindered the full dissemination of accurate HPV information.

HPV brochures and web sites have been inclusive of men but information specifically regarding cervical cancer is still mostly directed towards women (Hall et al. 2008). Additionally, cervical cancer information may not focus as much on transmission and strategies for disclosing to partners, which may add to the sense of stigma and isolation the female client may already feel (Hall et al., 2008).

How Information is Integrated into the Patient's Experience

Even when information is presented with clinical accuracy, ensuring that the client's personal view of their illness matches this is a challenge. The Common Sense Model of Illness Representation (CSM) states that people identify with an illness in five domains: identity (signs and symptoms of an illness), perceived cause, timeline (how an illness unfolds over time), controllability (prevention and treatment of an illness), and consequences (Marlow, Wardle, Grant, & Waller, 2009). Additionally, even when people are not personally diagnosed with an illness, they will conceptualize any illness using these five domains (Marlow et al., 2009). An additional feature of CSM is that an illness is experienced cognitively through facts as well as emotionally, culturally, and socially (Diefenbach & Leventhal, 1996). The pathophysiology of an illness is just one of many pieces of information that needs to be conveyed to patients and clients in order to encourage them to seek care and it may not even be the most compelling one (Diefenbach & Leventhal, 1996). If information provided in the clinical setting is not modified to address these complex needs, effective numbers of clients may not seek care.

Potentially Effective Interventions in Reducing the Psychosocial Burden of HPV

Despite the outlined problems with informational materials, it is unlikely that they will be replaced. Written materials in clinical settings are ubiquitous, cost-effective, and they allow clients to

have clinical information to refer to on their own time. The most potent way to strengthen the impact of information dissemination in the clinical environment is to combine it with individual counseling. Face-to-face or phone interaction with a nurse has been shown to improve follow-up rates when compared to only distributing pamphlets or letters (Mitchell & Hall, 2009).

Additionally, no pamphlet can replace the role of patient education. Nurses and other clinicians should spend ample time with patients clarifying the course of HPV and explaining the difference between high-risk and low-risk types of the infection (Perrin et al., 2006). It also is crucial for nurses and other health care providers to recognize that, although providing more information may increase client knowledge about HPV, this does not correlate with decreased anxiety (de Bie et al., 2011). It is imperative for clinicians to provide emotional support to their clients or be prepared to refer them for more extensive after-care as needed (Bertram & Magnussen, 2008). The relationship between the clinician and the client has a greater impact on reducing anxiety than does providing information alone (de Bie et al., 2011). Patients themselves reported that face-to-face support from health care providers, rather than mailed notification of test results, and more time to talk during office visits were most effective in reducing anxiety (Neill & Waldrop, 1998).

A Cochrane review of interventions to reduce anxiety in clients undergoing colposcopy only found sufficient evidence for playing music during colposcopy to reduce pain and anxiety (Galaal, Bryant, Deane, Al-Khaduri, & Lopes, 2011). There was insufficient evidence to either support or negate the use of counseling; video colposcopy; information using graphs, verbal information, or video; or information brochures used in conjunction with informational videos to reduce anxiety (Galaal et al., 2011). Although the review could not find supporting evidence for information brochures to reduce anxiety, the review did find that this intervention is important for informed consent and in reducing psychosexual dysfunction (Galaal et al., 2011).

Overall, the evidence has not uncovered one intervention that can completely eliminate anxiety. It may not be desirable to reduce anxiety as that response may actually drive clients to continue following-up with their health care provider (de Bie et al., 2011). Furthermore, it is understandable that a client will experience emotional discomfort when faced with a

change in health status. It is more prudent for clinicians to focus on reducing excessive anxiety rather than seeking to eliminate it entirely and assessing the client's needs in order to keep them in the system for follow-up (de Bie et al., 2011).

Assessment of the State of the Science of the Empirical Evidence

Because this inquiry sought to understand the complex mechanisms behind people's psychosocial responses, qualitative research designs were the most appropriate studies to utilize. A total of 14 studies were reviewed. Seven were qualitative studies, five were randomized controlled trials (RCTs), and the remaining two were quasi-experimental studies. The qualitative studies focused on the phenomenological experiences of study participants while the RCTs examined quantifiable impacts of various informational interventions (for example, using reliable tools to measure anxiety). The remaining documents were clinical practice guidelines or consensus recommendations.

The limitations of most of the qualitative studies are their small sample sizes, lack of generalizability to a larger population because of their focus on unique phenomena, and a lack of diversity within the samples (many of subjects were white, educated, middle-class, heterosexual, English-speakers, and partnered). Additionally, seven of the studies took place in the United Kingdom and Australia rather than the United States. For example, in a qualitative study by Mitchell and Hall (2009), the sample size was eight and included seven self-identified heterosexual women, six white women and no Latina or African-American participants, four were college-educated, and three self-identified as monogamous and partnered (married and unmarried) women (Mitchell & Hall, 2009). Furthermore, the age range was 18-62 with a median age of 31 (Mitchell & Hall, 2009). Such demographic homogeneity leaves out black and Latina women as well as newly immigrated women, all of whom are at higher risk for inadequate or no cervical cancer screening and therefore are at greater risk for cervical cancer mortality and morbidity (Saslow et al., 2012). Furthermore, many of the structured interviews in these studies were conducted by health care providers, which may have influenced the respondents' comments.

The greatest strength of the included qualitative studies is the use of phenomenology as a research method. This technique provides unique, descriptive information that can capture the essence of emotional

experiences and guide the formation of future qualitative and quantitative studies. In a study by Bertram and Magnussen (2008), 30- to 60-minute interviews were taped verbatim and analyzed. They uncovered that participants identified individualized information and supportive counseling resources as the most powerful interventions (Bertram & Magnussen, 2008). The strengths of the RCTs include larger sample sizes and the use of previously validated tools, such as the State-Trait Anxiety Inventory to measure anxiety levels (Kola & Walsh, 2011).

Although the sample sizes in the qualitative research studies were small, this is a common feature of this type of research. The quality of these studies, however, is high because the methods used for data collection were adequately described and limitations were clearly defined (Jones, 2010). For the RCTs included, the sample sizes were based on power analysis and research subjects were analyzed in the groups in which they were randomized to (Jones, 2010). Overall, the evidence consistently shows that, while informational interventions may not always reduce or alleviate anxiety in HPV-positive clients, combining information with a face-to-face interaction between the health care provider and the client may have a great impact on alleviating emotional distress.

The biggest gap in knowledge is the impact of online HPV information on anxiety and knowledge. There is a paucity of research regarding how this information is utilized by clients and if clinicians have enough knowledge about these resources to recommend them to clients. Bertram and Magnussen (2009) uncovered that participants viewed information obtained from the internet as private and allowed for more time to reflect on the information. But if the HPV information was derived from a general website about sexually transmitted infections, it was viewed as confusing and stigmatizing (Bertram & Magnussen, 2009).

Recommendations

Implications for Practice

Although further research needs to be conducted on tailoring informational interventions and testing the utility of other interventions in reducing anxiety in HPV-positive clients, there is enough evidence to urge a change in practice. Namely, more personalized care needs to be offered to clients facing an HPV diagnosis so that they navigate the complexity of the infection and stay in the layered screening and treatment process long enough for it to be effective.

Implications for Education

In order to enact these changes, nurses and other health care providers need training during their initial education and throughout their practice on how to best counsel HPV-positive patients and assess the value of the information they disseminate. Nurses also can take on a leadership role by utilizing their increased knowledge by creating evidence-based informational brochures.

Implications for Policy

More staff may be needed in order to meet the demand of providing individualized counseling. Personalized interventions may be more costly initially but they may be more beneficial in the long-run if they increase the number of clients who are adherent to recommended management guidelines. Furthermore, some anxiety-reducing interventions, such as playing music during colposcopy, are cost-effective and relatively simple to implement.

Implications for Research

Although this paper focuses on written materials distributed in the clinical setting, further research needs to be conducted on the accuracy and impact of online resources. Additionally, more RCTs are needed on the impact of various psychosocial interventions. Finally, the qualitative and quantitative research studies conducted in this field needs to recruit more diverse populations since the populations at greatest risk for cervical cancer morbidity and mortality are sorely underrepresented in the research.

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