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# A feminist information engagement framework for gynecological cancer patients

## The case of cervical cancer

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### Abstract

**Purpose** – The purpose of this paper is to present a three-part framework of information engagement for situated gynecological cancers. These particular cancers intertwine with medicalization of sexuality and gender power dynamics, situating information behaviors and interactions in women's socio-health perceptions. Using Kavanagh and Broom's feminist risk framework, the framework establishes functional and temporal parameters for sense-making and information engagement.

**Design/methodology/approach** – This paper employs a structured, reiterative literature review with emergent thematic analysis. Nine indices from medicine, information studies, and sociology were searched using combinations of five terms on cervical cancer (CC) and 14 terms on information engagement in the title, abstract, and subject fields. Results were examined on a reiterative basis to identify emergent themes pertaining to knowledge development and information interactions.

**Findings** – Environmentally, social stigma and gender roles inhibit information seeking; normalizing CC helps integrate medical, moral, and sexual information. Internally, living with the dichotomy between "having" a body and "being" a body requires high-trust information resources that are presented gradually. Actively, choosing to make or cede medical decision-making requires personally relevant information delivered in the form of concrete facts and explanations.

**Research limitations/implications** – The study covers only one country.

**Originality/value** – This study's information framework and suggestions for future research encourage consideration of gender power dynamics, medicalization of sexuality, and autonomy in women's health information interactions.

**Keywords** User studies, Behaviour, Women, Information literacy, Information studies, Information searches

**Paper type** Research paper

### Introduction

This paper presents a framework of information engagement for situated gynecological cancers. These particular cancers intertwine with medicalization of sexuality and gender power dynamics. Our framework posits the woman's personal medical situation as central to information engagement, broadly writ. We use cervical cancer (CC) as a case study of gynecological cancer. More specifically, we focus on CC in the USA where robust prevention and monitoring initiatives highlight the complexities and possibilities of information engagement. The resultant decision-making factors constraining patient autonomy are rooted in the dynamics of sexual well-being, gender role determinations, and complex medical information resources.



## Understanding the CC experience

The CC experience is actually a constellation of socio-medical considerations and their interventions that occur throughout the course of a potentially reiterative disease, starting from pre-pubescent vaccinations through end-of-life care. Prevention via a human papillomavirus (HPV) vaccine and regular screening significantly mitigates the risk of life threatening CC (Kara, 2011). The medical profession stresses that children as young as 9 should be vaccinated with the norm ranging from 11-12 for both sexes (Cifu and Davis, 2014). CC decision making thus stretches over most of a woman's life span. Diagnosing CC after it manifests symptoms leaves only high-risk intervention options (Cherath *et al.*, 2006). Both prevention and screening tools are stigmatized by placing health-care decisions in the context of socially sanctioned female sexual behavior. For example, having multiple sexual partners and getting other sexually transmitted infections (STI) are associated with HPV (Friedman and Sheppard, 2007; Johnson *et al.*, 2008; Juraskova *et al.*, 2011). CC itself is not an STI but is almost always caused by one, i.e., HPV infection. (That boys and men should be vaccinated is sometimes mentioned but the major stress is on the girls and women[1].)

Successful treatment, such as chemotherapy, radiation therapy, or surgery, may cause infertility (Carter *et al.*, 2013; Schwartz, 2009) and affect sexual well-being, e.g., painful sexual intercourse (Lammerink *et al.*, 2012). Gender dynamics and personal desires involving motherhood can quickly become part of the decision-making process. As with many other medical conditions in which prevention is under-funded and diagnosis requires access to specialized medical staff and services, CC is more common among women in low socio-economic communities (Ali *et al.*, 2012; Williams-Brennan, *et al.*, 2012). Racial and ethnic disparities may be tied to cultural norms of female sexuality and to beliefs regarding preventative care (Ashing-Giwa *et al.*, 2004; Daley *et al.*, 2011; Niccolai *et al.*, 2011).

## Broad socio-economic context of CC

Unlike other communicable diseases, CC creates isolated experiences. Once she is legally an adult, a woman's determinations on all aspects of the situation are, at least potentially, her own to make. Politically, however, health care policies establish limitations and opportunities regarding CC service access (Courtney-Brooks *et al.*, 2013; Tomljenovic and Shaw, 2012). Economically, research funding and marketing set the pace for CC treatment (Polyzos *et al.*, 2011) while community resource funding can control essentials, such as screening access (Krisberg, 2010). Socially, attitudes toward sexual behavior and women's health influence medical intervention access (Briones *et al.*, 2012; Fisher and Ronald, 2010). Technologically, online communities shape professional and lay discourse on health-care needs (Handelson, 2009; Johnston *et al.*, 2013). Medically, best practices evolve or stagnate with varying degrees of critical reflection (Dobson *et al.*, 2013; Leaver *et al.*, 2013). A separate analysis of those wider socio-medical community activities is outside the purview of this paper. Women personally concerned with CC live within their private situations with relatively little focus on these broader public contexts. The disease and its broader context certainly frame the personal experiences that women have, but our emphasis is on the individual's information engagement.

## CC feminist context: women's ways of knowing (WWK)

The feminist epistemological perspective of "women's ways of knowing" posits that the development of women's knowledge is situated in their self-concept as created by their private experiences as women within their individual socio-cultural contexts (Belenky *et al.*, 1997; Debold *et al.*, 1998). Three interwoven facets of women's

personal-intellectual growth are seen as drivers for life mastery: women's sense of self, the nature of their voice or expression of that self to others, and critical understanding of authority's worth. As these three develop women are, therefore, more likely to determine their own knowledge goals and to find the tools they need (Schweickart, 1998; Clinchy, 1998; Tarule, 1998). This woman-centric perspective firmly establishes our emphasis on the individual patient – not the disease and not the medical structure within which that disease is treated[2].

### **Information engagement from the WWK perspective**

Broadly defined “information engagement” consists of exploring, sharing, using, managing, searching (including monitoring and blunting), discovery (forced and serendipitous), resources (available and inaccessible), needing, avoiding, protecting, and understanding. We use the term from the WWK perspective to emphasize segments of the more established terms “information behavior” and “information seeking.” This emphasis draws on the WWK's core values regarding women's voices in their internal self-identity and their variably deliberate consideration of deeply personal life choices. This WWK perspective includes: the deliberate actions of CC patients – exploring, sharing, and using information; their information skills – management and searching (including monitoring and blunting); and the information matters beyond their control – discovery (forced and serendipitous) and resources (available and inaccessible). And, perhaps most crucial to this WWK perspective, it includes that which is internalized, i.e., needing, avoiding, protecting, and understanding information. To that end, we address the knowledge and understanding factors that influence women's personal CC experiences.

### **Literature structure**

This paper employs a structured, reiterative literature review. We identified nine relevant indices from medicine, information studies, and sociology: Library, Information Science and Technology; Medline; CINHALL Plus; Alt Health Watch; PsycINFO; Library Literature and Information Science Full Text; Internet and Personal Computing Abstracts; Academic Search Complete; and Gender Studies Database. In each of these nine databases results were limited to peer-reviewed articles published between January 2009 (the year the second vaccine was approved) and August 2013. Heavily cited articles from 2000 to 2008 were also considered.

All of the databases were searched as a group in EBSCOhost for the intersection of the two foci for the study: CC and women's information engagement. The terms used for CC are CC, cervix neoplasm, HPV, cervix, and cancer-women. The terms used for information engagement are “information” paired with needs, seeking, use, management, barrier, and tool. Forums for engagement were included, using the following terms: e-mail, database, online, internet, web, forum, and “social” paired with “media” and “network.” (Plurals were used where appropriate.) Each of the five CC terms was paired with each of the 14 information engagement terms.

Searches were conducted in the title, abstract, and subject fields, in that order. Each search continued until at least 30 hits were unproductive. The topical hits were examined individually to identify those which met three criteria: research (not, e.g. editorials and essays), patient-focussed (not, e.g. reports of medical treatment experiments or analyzes of policy issues), and information engagement focussed (not, e.g. using the internet as a survey delivery tool). On a reiterative basis, the resultant articles were compared to identify patterns in research findings on women's

engagement with CC information. The resultant framework emerged from this reiterative, thematically driven, multi-disciplinary literature analysis.

### **CC risk context: Kavanagh and Broom**

On a temporal basis, CC appears as a future possibility, as a current probability, as an in-the-now reality, as a life focus, as a constant potentiality, and more (See, for example, Roncancio *et al.*, 2013). Kavanagh and Broom (1998) place these perspectives of CC risk in a three-part framework of women's autonomy. First is the macro-level "environmental risk," i.e., those actions and realities that are outside the individual and beyond choice. They are "something that *happens to* a person [...]" (Kavanagh and Broom, 1998, p. 437; italics in the original). These environmental factors include socially constructed gender role norms, availability of treatment options, and culturally determined stigma regarding STI.

Second is the "embodied-self risk." Matters of social role (e.g. seeing oneself as a patient or as a mother), temporal expectations (e.g. expecting lifelong medical monitoring), and internal cohesion (e.g. firmly dividing the body and self) pose a risk to women's sense of position within the medical decision-making process.

Finally Kavanagh and Broom propose a "lifestyle risk," i.e., those personal choices that are part of the CC experience. The broader environmental risks and private, embodied-self-risks connect with these lifestyle risks as women make or cede their decisions on coping with the disease. These deliberate or passive behaviors include such actions as choosing to take the vaccine and completing screening every three years (1998, p. 437). Lifestyle choices are deceptively simple when viewed as context-free, autonomous determinations. However, their consideration, much less their implementation, must be considered in light of the individual's wider socio-personal context.

Kavanagh and Broom's three-part risk framework provides a lens through which the CC patient's private information choices can be analyzed in relationship to their public context. Just as these three framework components are inextricably connected, so, too, are the information perspectives. The disease, whether instantiated in a simple description of the virus or explicitly detailed in a pre-treatment consultation, requires women to live within an "environmental risk" context they do not control and to make, or cede, "lifestyle risk" choices about their health. Their "embodied-self risk" is influenced, even shaped, by their "way of knowing" the CC experience. Information as an epistemological force helps women give voice to their socio-medical intentions.

### **CC information engagement: the environmental, embodied, and lifestyle risk lenses**

That information is a tool for reducing uncertainty is axiomatic in information studies but CC requires a life-long awareness of that premise. Women's social environment always includes uncontrollable STI stigma. Their embodied self-changes as they move from pre-puberty to post-menopause. And, given sufficient socio-economic resources, women have the possibility of many information choices, for example, medical professionals, the internet, and television ads.

### **External forces: the environmental risk lens**

Three environmental forces influence virtually every CC patient's information experience throughout the course of the disease: social stigma, gender roles, and medically situated sexuality. Socio-cultural, as well as interpersonal, connections

generate assumptions and values that can be extended, challenged, or supported by information from medical professionals and social network members.

Social stigma is attached to many information messages provided by external sources (Friedman and Sheppard, 2007), some of which inhibit both the prevention of and screening for CC (Daley *et al.*, 2010a). The shame and fear of being judged regarding HPV status (Daley *et al.*, 2010a, p. 285) often outweigh medical information, which puts the focus on cancer rather than on stigmatizing STI. Information messages that focus on their overall health increase women's willingness to take the HPV vaccine and meet screening recommendations (Leader *et al.*, 2009; Juraskova *et al.*, 2012a, b; Maree and Wright, 2011). Recognizing the efficacy of actively shifting this external information emphasis, patient and public information movements have begun to normalize CC in order to facilitate women's medical and social ability to address it (Cook, 2013; Dyer, 2010; Moore-Monroy *et al.*, 2013).

Gender roles stand out in terms of responsibility for HPV protection and the socially acceptable behavior of women. Medical, social, and political influences on socially embedded information messages posit young women as the sole focus of CC concerns. However, both sexes get and transmit HPV. Both sexes get cancer from it. Both sexes would benefit from the vaccine. Indeed, the pharmaceutical company Merck urged the FDA to approve the HPV vaccine Gardasil for men on the grounds that they give HPV to women, as well as other men, and those men are at risk of developing anal, throat, and penile cancers (Thompson, 2010, p. 120). Even college-educated men have relatively limited understanding of their role in transmitting HPV and, by extension, their role in increasing women's CC risk (Chan *et al.*, 2012; Daley *et al.*, 2010b). Positioning HPV as an infection from which women alone need protection abrogates the co-responsibility that men have for the safety of their sexual partners, including the possibility of CC for their female partners (Thompson, 2010, p. 123). HPV education and social information that focus exclusively on women tend to make women believe that they bear the responsibility for the sexual health of both partners (Bynum, 2011; Philip *et al.*, 2012). Externally generated information on the connections between HPV and CC assume much the same relationship to gender roles as does unplanned pregnancy (Cook, 2013). "She didn't take the vaccine so she got HPV" mirrors "She didn't use protection so she got pregnant."

Medically situated sexuality begins at the first vaccine and eventually includes fertility and sexual well-being issues (Greimel *et al.*, 2009; Polzer and Knabe, 2012). Information on that relationship, however, is rarely available. Many medical professionals start safe-sex education conversations with the children and young women they vaccinate (Askelson *et al.*, 2011) but their information focusses on the physical, rather than the emotional, aspects of HPV and CC. Socially, this deliberate separation of STI and sexuality as they relate to CC blurs the lines between medical facts and moral judgments. Parents who think of the vaccine decision in terms of their daughters' potentially more rapid move toward sexual activity tie medical information to personal sexuality values (Reiter *et al.*, 2009). In CC sufficiently advanced to require a number of medical specialists, information on sexuality is also ignored. In some studies, however, nurses seek, provide, and share information on sexual identity and desires for women whose external risks are viewed as entirely medical (Schwartz, 2009).

#### *Internalized-self: the embodied risk lens*

At each moment of the CC experience women's internalized sense of self is privately instantiated in terms of self-perception and autonomy in relationship to CC. This inner

perspective may well change in reference to the external influences described above but it is inherently a private evolution. Perceiving a lack of internal cohesion (e.g. firmly dividing the body and self) poses a risk to her position within the medical decision-making processes. In particular situations or processes, does she speak of and present herself as a woman or does she present as a physical persona? Particularly when the CC progress requires substantial medical intervention, this difference between “having” a body and “being” a body becomes problematic (Blomberg *et al.*, 2009). To “have” or “own” your own body has its problems, as when physically active personal relationships must be viewed from the prism of the HPV, but autonomy is the standpoint from which judgments are made. Surgery, for example, leaves many women with a deepened awareness of their altered bodies, bodies which they own (Sekse *et al.*, 2010). Information factors in this internalized-self-cluster into two categories – the affective and the cognitive.

Affective factors involve trust, emotional adjustment, fear, anxiety, and possible feelings of shame. Trusted information sources, primarily those medical and social connections that were strong before CC questions arose, have a great deal of influence on affective responses (Casillas *et al.*, 2011; Hill and Gick, 2013; Krieger *et al.*, 2011; Miller-Ott and Durham, 2011; Ratanasiripong *et al.*, 2013).

Information delivery influences emotional adjustment. Phased information delivery, e.g., facts delivered in small chunks so that there is time for emotional adjustment, can mitigate the anxiety and shame arising at the initial diagnosis. The fear and anxiety that CC victims feel while waiting for medical determinations are lessened when information is provided gradually (Kosenko *et al.*, 2012a; Tejada *et al.*, 2013; Waller *et al.*, 2007).

Explanatory information that clarifies the medical nature of CC and its terminology, can allay some of the fear of the unknown. Knowing what to expect strengthens self-efficacy, particularly at action points such as undergoing the first screening or receiving problematic test results (Brown *et al.*, 2011; Daley *et al.*, 2011; Drolet *et al.*, 2012).

Trust in medical expertise and personal fortitude shift emotional responses toward confidence and, in some cases, optimism (D’Orazio *et al.*, 2011). At a gross level, simple, factual information is of value in shifting internalized affective self-perceptions – a shift which may well support a cognitive change in personal health beliefs.

Cognitive factors that challenge health beliefs may require a restructuring of self in relationship to CC and, indeed, sexual health overall. Older women, for example, who are surprised to learn that they continue to need screening must not only alter their CC beliefs but, if they have not done so already, begin to review the value of their sexual well-being (Gravitt *et al.*, 2013; Montgomery and Smith-Glasgow, 2012; Montgomery *et al.*, 2010). Unexpected information on the relationship between CC and HPV pushes young women to view an immediate need for STI prevention in terms of a lifetime need to avoid CC (Juraskova *et al.*, 2011; Krieger and Sarge, 2013).

Impersonal, and therefore private, information sources (e.g. drug company television commercials; Kelly *et al.*, 2009; Litton *et al.*, 2011; Mueller *et al.*, 2012) give women control over the pace at and degree to which they assimilate the relationships between CC, HPV, and their sexual well-being. The internet is, of course, a commonly used source of information at all stages of the CC experience (Daley *et al.*, 2010a; Hilpert *et al.*, 2010, 2012; Keelan *et al.*, 2010; Kontos *et al.*, 2012; Mueller *et al.*, 2012; Thorburn *et al.*, 2013; Tran *et al.*, 2010). Its anonymity and the variety of information forums facilitate women’s control over what information they acquire, or, at least, offers them the freedom to explore and examine information that addresses the full constellation of CC situations.

*Active choice: the lifestyle risk lens*

Within the context of their internalized selves and their external influences, women make their own choices regarding CC – including the choices not to act and to cede medical decisions to others. The information components of their actions most commonly pertain to gaining sufficient and trusted information, control over when and with whom to share information, and control over the intensity of information engagement. None of these components necessarily leads to optimal CC choices.

Sufficient and trusted information coalesces around customization. Personally relevant facts and explanations that fit into women's lives generally encourage active choices. For example, college students are more likely to get vaccinated and screened if they know that they have a personal risk. Upon learning that multiple sexual partners constitutes a CC risk they tend to seek out the vaccine (Allen *et al.*, 2009; Chao *et al.*, 2010; Simwale *et al.*, 2011).

In this vein, peer-generated information is commonly trusted even if it is inaccurate. A number of college women believe that a CC screening also tests for conditions such as vaginal infections, gonorrhea, AIDS, and pregnancy (Daley *et al.*, 2013). Despite this inaccurate information, most young women who know about the vaccine's value intend to get it (Chan *et al.*, 2012) and continue to get screened (Price *et al.*, 2011).

On a micro-level, treatment information on deeply personal subjects, e.g., fertility and sexual well-being, is more valued when presented in concrete terms situated in the woman's unique experiences (Christman *et al.*, 2001). Trusting any information source is often difficult for women with marginalized sexual experiences. Survivors of rape and other sexual assaults are at a higher risk for CC but they are less likely to trust that information resources recognize or value their experiences (Coker *et al.*, 2009). Some lesbians have little knowledge of screening's value and report that a fear of discrimination keeps them from routinely making use of it (Tracy *et al.*, 2010).

Control over the timing and the nature of sharing their own information about HPV or CC status factors into decisions to move from the deeply private to the public. While women should be able to choose when and to whom they disclose their CC, it is expected that the HPV diagnosis will be shared with current and past sexual partners. As with any STI, the individual's health condition can seriously impact others. One difficulty lies in knowing who should be informed when the date of original infection is unknown. Telling ex-partners who are not in danger of infection leaves the patient open to judgment and blame (Kosenko *et al.*, 2012b). Of course, women need to get information from their partners as well. Such information is more likely to come from men whose sexual relationships are relatively stable (Arima *et al.*, 2012).

Additionally, sharing diagnosis with friends and family breaks the protective silence that is built around that intimate knowledge (Hutson *et al.*, 2011). Some women share their information as a means of warning others or as an element of life planning with a partner (Daley *et al.*, 2010a).

Having control over the intensity of information engagement is one means of coping with the uncertainties in the CC diagnosis phase. The standard "watch and wait" approach to initial reports of cell abnormalities can be difficult to endure. Some results require women to choose continual monitoring via regular screening. For those with the means to do so, gaining additional diagnostic information via a colposcopy provides clarification (Waller *et al.*, 2007). Both active seeking and casual scanning of public media (Kelly *et al.*, 2010) suffice for women with a high tolerance for medical uncertainty. Women with a low tolerance tend to seek additional information, particularly on task-based options, e.g., the timing of follow-up appointments (Rosen *et al.*, 2010). Information seeking



is essential to active coping strategies in both social and formal situations. For example, asking for help in planning (D’Orazio *et al.*, 2011) is a social act, while seeking information from organizations would be formal (Stevens and Tiro, 2011).

### Information engagement framework for gynecological cancer patients

Building women’s information engagement on the risk framework of situated CC experiences, our framework triangulates the environmental, internalized-self, and lifestyle choice lenses. Kavanagh and Bloom’s (1998) feminist epistemological perspective echoes the “women’s ways of knowing” knowledge construction (Belenky *et al.*, 1997) by positioning women’s private and public voices as a form of social empowerment. Using a structured, reiterative cross-disciplinary literature review with an initial set of 14 terms in nine databases, our emergent framework inculcates the life-long CC experience.

In this framework, the environmental lens hones in on issues of social stigma, gender roles, and medically situated sexuality. Women shape, receive, and live within the framework of these socially constructed norms. Over time, this lens evolves at the macro level (e.g. expectations of women’s social options) and at the personal information-interaction level (e.g. information quality and access) (Table I).

The embodied lens clusters information experiences of affect (primarily anxiety and shame) and cognition (health beliefs and privacy). Here, women’s internalized sense of self interweaves emotions (particularly negative ones) and understanding of CC. This lens develops in terms of women’s empowerment and sense of CC control.

Kavangh/Bloom lenses	WWK sense of authority, self, and voice	Temporal factors of society, self-understanding, and learning	Support for CC information engagement effectiveness
Environment lens: shapes CC in terms of social stigma and gender roles; medicalizes sexuality	The environment lens posits authority’s classification of HPV as a woman’s problem, thereby inhibiting her personal options in medical decision making	The environment lens posits social temporal changes in CC’s stigma and gender roles among society at large	The environment lens suggests the value of reducing information barriers of shame; it recognizes that society’s medical, moral, and sexual information on CC are poorly integrated
Embodied-self lens: places CC in frameworks of sexual identity	The embodied-self-lens posits CC as division between the individual’s “being” a body and “having” a body	The embodied-self-lens posits internalized temporal changes in CC’s influence on individuals’ internal cohesion social role	The embodied-self-lens suggests the value of building trust in CC information resources; it recognizes the effectiveness of gradual information delivery and anonymous resources in which the affective and cognitive intertwine
Lifestyle lens: addresses CC by the decision to make or cede choices	The lifestyle lens posits individuals’ voices as controlling the timing of and degree to which CC/HPV information is used and shared	The lifestyle lens posits temporal changes in building CC health information literacy whether it is developed deliberately or grows as a by-product of action	The lifestyle lens suggests the value of providing personally relevant information in which concrete facts and explanations are carefully combined

**Table I.**  
Kavangh/Bloom  
lenses on CC  
information

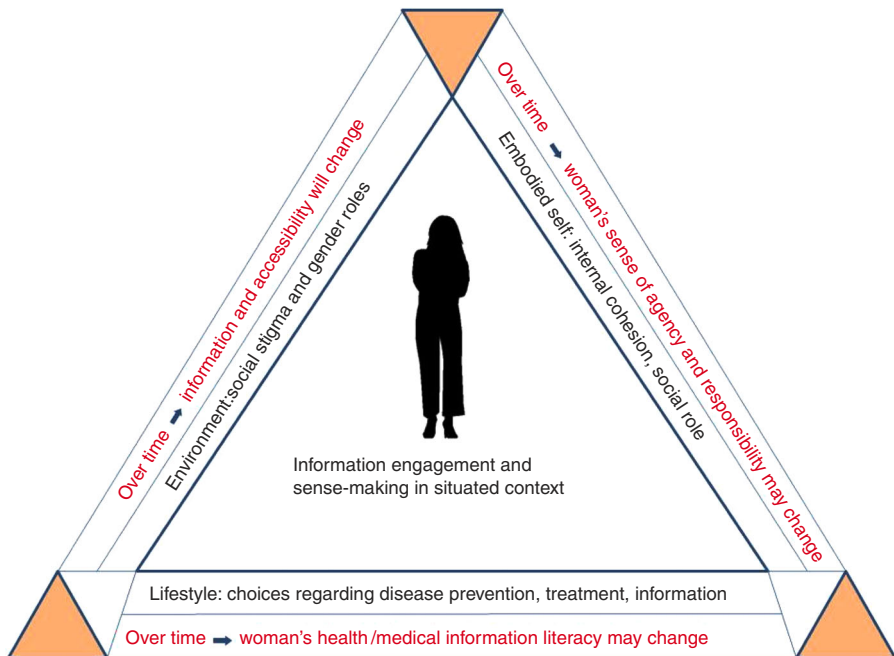
The lifestyle lens entails gaining, controlling, and sharing information as well as the degree of intensity of information engagement. Women's CC health decisions and lifestyle choices include high-risk moments (e.g. choosing among treatment options) and ongoing behaviors (e.g. deciding to stop CC screening). This lens develops in terms of women's health information literacy, both formal and organic (Genuis, 2012, 2013; Kosenko *et al.*, 2012a) (Figure 1).

At the center of these three lenses and their temporal boundaries stands the woman who lives with CC from that first pre-pubescent vaccine through decades of screening and, for many, treatments for cancer that has been identified, monitored, and/or metastasized. The framework's three-segment structure, within its ever-moving temporal contexts, provides opportunities for creating effective information support and services that incorporate relevant functions across women's environmental, embodied self, and medical lifestyle choices.

Gynecological cancers attack sexual vitality and fertility. CC casts a shadow over both with its "watch and wait" monitoring, regular screening, and social stigmas. This framework encompasses that complexity in full recognition that women's unique experiences fit therein with infinite variation. That which comes from without and that which comes from within do not lead to life choices. Women live at the center of three and, quite often, the three are experienced as one.

### Implications

Several well-established health information and health-belief frameworks provide powerful, effective insights into the highly personal world of individual efforts to make sense out of the problems their bodies are having. Our nascent framework makes a modest contribution to that discourse.



**Figure 1.**  
Information engagement framework for gynecological cancer patients

The psycho-social medical experiences at the heart of David Johnson's (1997) powerful work incorporate the complexities of information resources and behaviors. *Health Information Seeking* (Johnson and Case, 2012) recognizes that facts sought by patient proxies, statistics delivered contextually, explanations drawn from dubious internet sources, and other forms of information are juxtaposed with people's means of participating in the information aspects of the role that the cancer plays in their lives.

The well-established health-belief models of Calnan (1982) and Rosenstock (1988) support policy consistency in prevention and early detection of health problems. These models are also relevant to CC screening (Garcés, 2006). Miller's (1987) work identified patients' use of monitoring to find new information and their use of blunting to avoid material that might challenge beliefs or decisions values that in-the-moment aspect of health experiences. Similarly, patient education and evidence-based practices increasingly build on the experiences that individuals have with gynecological cancer (Clark *et al.*, 2012; Kessler, 2012; Wang *et al.*, 2010; Clarke and Bailey, 2010; Hart *et al.*, 2011). Coming from a health perspective, however, both education and practice assume the value of concrete medical action.

Our framework assumes the woman's potential agency in both information engagement and medical choices. She constructs her sense of the place that CC will have in her life, its effect on her sexuality and sexual well-being with norms established at society's macro level. At the micro level, her personal relationships might be affected. As with any patient, her information may be deliberately ignored, rejected, scrupulously avoided, eagerly sought, or otherwise engaged. Her medical choices may be passive, forced, ad hoc, or otherwise determined. Placing the woman at the center of this power constellation of social and personal frameworks provides an additional avenue for acknowledging her life choices and meeting her information requests.

### Future research

Any fledgling framework requires testing and ours is no exception. We propose that the initial follow-up study move from our multi-disciplinary literature analysis directly to examining the framework with the girls and women involved in CC experiences. Longitudinal in-depth interviews, observations, focus groups, and document audits (with all due ethical protocols firmly in place) would provide a rigorous examination of the framework's three temporal elements. All three elements (personal agency, social information availability, and personal health literacy) certainly exist in general terms but their relationship to CC requires original data.

In addition to testing these changes over time, we need to understand the impact of such changes. The lifestyle lens needs to be applied to patient autonomy and responsibility in the instances of varying risk-intensity, such as the relatively moderate-intensity choice to get the vaccine and screening (Mishra and Graham, 2012). Does the repeated screening experience encourage a willingness to make choices when the patient faces, say, the stigma of an HPV diagnosis? Does specific reference to gender power dynamics and/or patient recognition of the socio-economic political aspects of CC influence the willingness to share information (Audet *et al.*, 2012; Zhao, 2010; Kritcharoen *et al.*, 2005; Mishra and Graham, 2012)? Can the framework be used to increase the efficacy of health literacy and resources as reflected in the work of Bynum *et al.* (2013) and Helitzer *et al.* (2009)? Using sides of the framework diagram, for example, should the "environment's" information resources become increasingly focussed on sexual well-being as the "embodied self" grows stronger? Additionally,

public health and physician-driven education can be reconceptualized on a longitudinal basis to strengthen the information's cohesion with the patients' agency.

In terms of the environmental lens, research studies need to explore male responsibility for and experiences of vaccination and HPV (Gerend and Barley, 2009; Crosby, *et al.*, 2012; Pierre Joseph, *et al.*, 2014), as well as related sexual life-style actions (Maree and Wright, 2011). Medicalizing sexuality across biological development stages from pre-puberty to initial sexual activity, child-bearing, and post-child-bearing years could well influence the complexity of extended health concerns such, as concomitant diseases and co-morbidity (Friedman and Sheppard, 2007; Polzer and Knabe, 2012). Social norms are instantiated in public policy at local and national levels. The "inherent tension between population based public health initiatives and individually-oriented health-care provision" requires examination in light of stigmatized gynecological cancers (Blomberg *et al.*, 2011, p. 112; Bodemer *et al.*, 2012; Cofta-Woerpel *et al.*, 2009; Genuis, 2013; Parkhurst and Vulimiri, 2013; Pitts and Adams Tufts, 2013). The power dynamics of information intermediaries, proxies, and gatekeepers bear review particularly in the context of social and online communities (Ache and Wallace, 2008).

In the matter of the embodied or internalized-self-lens, we have very little information on how intimate relationships facilitate long-term self-efficacy. Such relationships might include daughter-mother-grandmother (Ackerson, 2012; Cox *et al.*, 2010; Dempsey *et al.*, 2009), or spousal-significant other relationships (de Bocanegra *et al.*, 2009; de Groot *et al.*, 2005), or peer/friend relationships (Chilton *et al.*, 2005; Miller-Ott and Durham, 2011). Does belonging to an online or in-world social group reinforce or otherwise shape young women's awareness of "having" a body vs "being" a body?

Finally, the framework needs to be extended to other forms of gynecological cancer and other socio-economic settings. If it proves robust enough, the framework should be used in contrast studies with other gender-based cancers such as breast and prostate cancers. We need to study the degree to which it proves efficacious in developing countries with less robust medical and information systems than that of the USA (Arbyn *et al.*, 2010; Badar and Anwar, 2011; Forman *et al.*, 2012).

## Conclusions

Taking a feminist epistemological perspective, this paper posits a woman-situated information engagement framework for gynecological cancer using CC as a case study. Based on the work of Kavanagh and Bloom, three lenses of investigation are suggested to deepen insight into women's information engagement: environmental, embodied self, and lifestyle lenses. These cancers put sexuality, sexual well-being, and fertility at risk, and that creates a complex, life-long decision-making situation for the woman involved.

Established, general models (e.g. Rosenstock, 1988; Calnan, 1982) provide powerful, testable lenses for the universal study of health belief systems. This framework augments that work by holistically examining a tightly interwoven trio of women's situated cancer concerns that run on a life-continuum rather than a disease-continuum. By placing a condition that spans pre-puberty to end of life into the Kavanagh/Bloom power dynamic, we have extended these established models on a highly specific basis.

The framework and suggestions for future research encourage consideration of gender power dynamics, medicalization of sexuality, and autonomy. Information studies can provide concrete information strategies and tactics that contribute to various forms of gynecological cancer prevention and treatment. This paper proffers a unique framework from which to consider those contributions.

## Notes

1. Biologically, there are more than two sexes and socially the variations on gender identity are legion. In addressing gynecological diseases, however, this paper assumes males and females.
2. The term “patient” is used to emphasize the CC context. We fully recognize that women may well self-identify by social role (e.g. mother), professional role (e.g. engineer), gender role (e.g. nurturer), or other perspective. Additionally, some women may not be “patients” in the sense of being under a doctor’s care, particularly minors who are given the vaccine with no control or immediate medical diagnosis.

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