

Psychosocial Aspects of Cervical Screening

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Cervical Screening

- Cervical cytology screening highly effective in detecting premalignant conditions
- Dramatically decrease incidence and mortality of cervical cancer
- Pap test is a simple procedure
- More than 100,000 cervical cytology test done yearly through the Cervical Screening Program (CSP) in HK
- About 5-10% will have abnormal cytology results
→ colposcopy, follow-up or treatment

Cervical Screening - Anxiety

- Women experience high levels of anxiety and negative emotional responses at all stages of cervical screening
 - Invitation for screening
 - Fear of discovery of cancer, embarrassment, fear of the procedure
 - Abnormal results
 - Asymptomatic and did not consider themselves at risk of cervical cancer
 - The routine nature of screening that intensify anxiety
 - Being referred for and attending colposcopy
 - Increase anxiety levels

Response to Abnormal Results

- Sense of vulnerability, uncertainty, sense of loss of control, confusion, fear, anxiety
 - Fear of having cancer (69-100%)
 - Fear of infertility, loss of sexual response and functioning (68%)
 - Disruption of body image – less attractive, unclean (62%)
 - Fear of medical procedures (65%)
 - Infect sexual partners or family members (26%)
 - Feelings of guilt – punishment for sexual activity
 - Attribute the abnormality to early sexual activity, use of OC pills, previous infection etc

Colposcopy

- Associated with high levels of anxiety - mean STAI~45 (State-Trait Anxiety Inventory - a measure of anticipatory anxiety)

Studies		STAI Level (20-80)
	Normal women	36.2
Richardson et al 1996	Pre-colposcopy	45.2
Howells et al 1999	Pre-colposcopy	48.8-50.36
Kincey et al 1991	Pre-colposcopy	47.1
Marteau et al 1990	Pre-colposcopy	42-51

- Even higher than that before elective surgery (Johnson 1980) and similar to the anxiety levels in women following an abnormal screening test for fetal abnormality (Marteau 1988)

Johnson M et al. Anxiety in surgical patients. Psychological Medicine 1980;10:145-52
Marteau TM et al. Screening for Down's Syndrome. BMJ 1988;297:1469

Pre-colposcopy Distress and Anxiety

- Apprehension about the procedure
- No idea about colposcopy and what will happen during the procedure
- Concern about pain and discomfort
- Loss of sexual or reproductive function after the procedure
- Some women do not know the location of the cervix, confuse with examination of the uterus, biopsies might be taken

Anxiety Levels

- Appropriate level of anxiety can alert the individual and mobilize coping skills:
 - May provide the necessary motivation to adhere to recommended management
 - Healthy
- Excessive anxiety:
 - Adverse consequences
 - Affect information processing, impairing the ability to process complex information and leading to a bias towards processing threatening information
 - Denial, avoidance, indecisiveness

Adverse Effects of Anxiety

- Affect the psychological, behavioral and social lives of women and their families
- Sleep disturbance (up to 40%), irritability, depressed affect, crying episodes, outburst of anger, weight change, loss of sexual interest (up to 50%), disruption in sexual relationship, impairment in daily activity (up to 25%)
- Initial reactions difficult to identify:
 - Suppressed by the shock of an unexpected result
 - Reluctant to disclose their anxiety
 - Develop over time
- Further complicated by concurrent stressors such as work, family, relationships, financial difficulties, other health problems, limited social support
- Decrease pain tolerance during colposcopy
- Adherence to follow-up protocols to prevent cervical cancer, high loss to follow-up rate

Healthcare providers are responsible to:

Identify the causes and factors contributing to the anxiety of screening, abnormal results and colposcopy

Develop strategies to reduce the anxiety and enhance compliance to follow-up protocols

Factors Influencing Anxiety

- Being notified of abnormal cytology
- Insufficient information that is specific to their needs
- Confusion with their own sexual behaviour, as they did not have multiple sexual partners
- Did not have a partner
- Experienced a long waiting time for colposcopy (subjective experience)
- Myths and stigmatization of having STD
- Experienced additional emotions like anger and sadness
- Other psychological factors e.g. concurrent stressors

Interventions

- Start before cytology screening with anticipatory guidance and reassurance
 - Forewarning that the result may be abnormal
 - Most abnormal results are managed with surveillance or effective low-impact interventions; infrequently implies cancer
 - Can reduce the reaction of shock and disbelief when a women first learns that her test is abnormal

Education and Information

- Providing information before surgery has been shown to have a positive effect and improve post-operative recovery (Contrada 1994, Johnson 1993)
- Conflicting results to decrease anxiety for patients with abnormal cervical cytology referral for colposcopy
- Information leaflets alone did not significantly reduce anxiety levels, but they did increase knowledge levels and improved patient quality of life by reducing psychosexual dysfunction (Marteau 1996)
 - Written patient information - no guarantee that she will read it or understand it or reassure her
 - Verbal information - provide opportunity to ask questions
 - High anxiety may obliterate understanding a comprehensive message from the healthcare worker
- Higher mean state anxiety scores in patients who were not satisfied with the information provided
- Content, format and timing of information provision are crucial

Contrada RJ et al. Psychological preparation for surgery. International Review of Health Psychology 1994;3:219-66

Johnson M et al. Benefit of psychological preparation for surgery: a meta-analysis. Annals of Behavioural Medicine 1993;15:245-56

Marteau et al. Reducing anxiety in women referred for colposcopy using an information leaflet. B J Health Psychol 1996;1:181-9

Education and Information - Content

- Basic information, education, support and reassurance
 - Nature and cause abnormal cytology, natural history of HPV induced lesions
 - Cervical cytology is primarily a test for cells that may lead to cancer if not detected and treated
 - How common is HPV (naturalization and de-stigmatization) and the low risk of cancer for most infected with HPV
 - Address patients' concern such as fear of cancer (not confirm cancer but requires further investigation), loss of infertility, loss of sexual function – correct misconceptions
- Implications of an abnormal smear and reasons for further diagnostic procedures and treatment options
- Information for colposcopy
 - Basic anatomy, what is colposcopy, what will be done and the actual steps, length of examination, pain and discomfort during colposcopy and after-effects of colposcopy
- Stress the importance of compliance to follow-up

Education and Information - Content

- Brief, simple and comprehensible
- Avoid technical terms to reduce misinterpretation
- Reduce anxiety if it fosters a sense of control over the outcome
 - Most beneficial when the women's preference for information is matched with the amount and specificity of the information she receives, and in higher socioeconomic groups
 - Further Explore:
 - How much does the patient know
 - How much would she like to know
 - How much does she want to be involved

Education and Information - Format

Studies	Intervention	Results
Wilkinson et al 1990	<u>Leaflet</u>	<ul style="list-style-type: none"> • <u>STAI[^] reduced</u>
Howells et al 1999	Leaflets	<ul style="list-style-type: none"> • No difference
Marteau et al 1996	Appointment letter only VS <u>short booklet[#]</u> VS long booklet [*]	<ul style="list-style-type: none"> • Increased in <u>knowledge</u> for both booklets • Short booklet <u>reduced anxiety</u> (long booklet did not)
Byrom et al 2002; Chan et al 2004	Pre-colposcopy information (written + video) with <u>counseling</u> (colposcopy nurse) VS information only	<ul style="list-style-type: none"> • Increased in <u>knowledge</u>, higher attendance rates and better compliance to follow-up • No difference in STAI
Freeman-Wang et al 2001	Information <u>leaflet+video</u> VS Information leaflet	<ul style="list-style-type: none"> • Significantly <u>decrease STAI</u> in leaflet+video group

[#]Short booklet – Procedure of colposcopy, coping techniques e.g. relaxation and distraction focusing and information on outcome (619 words)

^{*}Long booklet – Etiology and more detailed description of procedure and outcome (3465 words)

[^]STAI – State Trait Anxiety Inventory

Education and Information

- Timing of information
 - Anticipatory education is recommended since providing information at the time of colposcopy is time consuming and ineffective
 - Most women prefer to receive information at the time they were told to have an abnormal cytology result
- Source of information
 - May prefer to receive information from their primary care practitioner who took the pap smear rather than the referred specialist colposcopist
 - No strong evidence that pre-colposcopy counseling can reduce anxiety

Waiting Time

- Interval between abnormal result and colposcopy is the most anxious time in more than 50% women
- Waiting time for colposcopy depends on the severity of abnormality
- However, anxiety level is not related to the severity of the abnormality
- The subjective experience of a long waiting time to colposcopy significantly increased anxiety level (Bekkers 2002)
- Anxiety and distress significantly decreased immediately after colposcopy and continue to decreased in the subsequent 6 months (Richardson 1996)

During Colposcopy

- Improve appointment-scheduling to reduce waiting time in the clinic
 - Women experienced high anxiety immediately before colposcopy and a busy waiting area engendered the feeling of being hurried and reluctant to ask questions
- Information sharing at the time of colposcopy
 - Interactive, supportive and individualized
 - Orientation – what is seen (real time image), heard, touched and smelled
 - Patient – how they can make themselves comfortable during the procedure

Pain and Discomfort During Colposcopy

Study	Intervention	Results	Remarks
Chan et al 2003	Playing slow-rhythm <u>music</u>	Significantly reduced pain (VAS) and STAI anxiety score	Promote relaxation and decrease anxiety, resulting in a higher pain threshold; distraction from painful sensation and reduce anxiety responses
Walsh et al 2004	<u>Video colposcopy</u>	Significantly decrease in state anxiety score and less pain	Greater sense of involvement and control; greater understanding of the condition
Church et al 2001	Ibuprofen VS Benzocaine gel VS Both VS Placebo	No significant difference in reducing pain (VAS) when used either alone or together over placebo	

Chan YM et al. *The use of music to reduce anxiety for patients undergoing colposcopy: a randomized trial. Gynecologic Oncology* 2003;91:213-7

Walsh et al. *Anxiety levels in women attending a colposcopy clinic: a randomised trial of an educational intervention using video colposcopy. Patient Education and Counseling* 2004;55:247-51

Church L et al. *Analgesia for colposcopy: double-masked, randomized comparison of ibuprofen and benzocaine gel. Obstet Gynecol* 2001;97(1):5-10

Post Colposcopy

- Anxiety found to be significantly decreased immediately after colposcopy
- Still >60% anxiety score above norm 1 week after colposcopy (waiting for Bx results)
- Understanding the physical and psychological after-effects after colposcopy can develop strategies to ameliorate anxiety and improve compliance to follow-up
- TOMBOLA Trial (Trial Of Management of Borderline and Other Low-grade Abnormal smears) –
 - 6 weeks after colposcopy, cervical biopsies and LLETZ for low grade cytology
 - Physical after-effects (pain, bleeding, discharge)
 - Psychological after-effects (factors affecting distress)

TOMBOLA Trial – Physical After-Effects

- Pain, discharge, bleeding
 - Colposcopy alone – 14-18% pain, bleeding or discharge (3-5% mod or severe)
 - Colposcopy and Biopsies – 50% pain or discharge (14-28% mod or severe), 79% bleeding (21% moderate or severe)
 - LLETZ – about 60% pain or discharge (30-40% mod to severe), 87% bleeding (50% mod or severe)
 - Median Duration –
 - Pain 1-2 days
 - Bleeding / discharge 2-3 days for colpo+/- Bx, 10-12 days for LLETZ
- Change in 1st menstruation (Timing, Flow, Duration, Discomfort)
 - Colposcopy only: 29%
 - About 10% earlier, heavier, longer, more discomfort
 - Colposcopy + Bx: 43%
 - 8% earlier, 25% heavier, 13% longer, 18% more discomfort
 - LLETZ: 71%
 - About 10% earlier, 40% heavier, longer, more discomfort
- Interventions – information on physical after-effects may help to reduce distress

TOMBOLA Trial – Psychological After-Effects

- Impact of Event Scale (IES) at 6 weeks after the last procedure
 - Measure subjective psychological distress associated with a specific stressful or traumatic event
 - Normal colposcopy – 21% significant distress
 - Abnormal colposcopy – 42% significant distress
- Factors affecting psychological distress
 - Pre-colposcopy anxiety, pain or discharge after colposcopy (link between physical and psychological after-effects)
 - Normal colposcopy
 - Worries about having sex, dissatisfaction with support from other people
 - Abnormal colposcopy
 - Younger age, CIN 2/3, bleeding after colposcopy, worries about cancer
- Interventions – information, reassurance and support

Women's Experience of Colposcopy

- Influenced by 3 concepts – Feelings, choices and time
 - Positive staff attitude (friendliness, reassurance, clear communication, personalized the delivery of information) alleviate emotional anxiety
 - Staff asking their preference – use of monitors to visualize the cervix, gender of colposcopist (inform in advance), number of people in the examination room
 - Short waiting time, not feeling rushed during their appointment and staff taking time to explain the procedure and how it might feel
- Sense of relief, reassurance and gratitude after the appointment was over
- Clarification of the diagnosis and gaining understanding of how the condition is managed

Compliance to Follow-up

- Besides interventions to alleviate anxiety by meeting women's informational and emotional needs
- Identify high risk non compliance groups
 - Young, unmarried, poorly educated, low socioeconomic status
- Social Support
 - Additional barriers of non compliance include transportation difficulties, childcare needs, time constraints
- Psychological Support
 - Conflicting health beliefs, aversion to medical treatment, hopelessness about cancer, cultural difference
- Structural telephone counseling to address informational, psychological and logistic issues after a missed scheduled colposcopy / follow-up – highly effective than just a standard telephone reminder or confirmation
- Well organized clinic workflow and care pathway
 - Reduce confusion of follow-up schedules and improve compliance

Psycho-social Impact of HPV Testing

(1)

- Causative link between HPV infection and cervical cancer
- Increasing clinical application of HPV testing in cervical cancer screening
 - (1) Triage of mild cytological abnormalities to select for colposcopy
 - (2) Primary screening test – adjunct to cytology / standalone test
 - (3) ‘Test of cure’ following treatment of CIN
- Community knowledge about HPV infection may not catch up with the medical advances
- Many still regard HPV infection as a STD only and misconceptions* are common:
 - 66.7% Infected individuals are sexually easy
 - 31.8% An individual with only one lifetime sexual partner will not be infected
 - 34.8% One should keep a social distance from those who are infected
 - 50.9% Women are infected because their partners have been unfaithful
 - 66.9% Women are infected because they have more than one sexual partner
 - 36.2% Women who are infected give other people feeling of “dirtiness”

Psycho-social Impact of HPV Testing (2)

- A positive HPV test may have a prolonged adverse psychosocial and psychosexual impact
 - Stigmata of sexually transmitted disease
 - Depression, anguish, anger, loss of self-esteem, and hostility toward the person believed to be the source of the infection
 - Link of cervical cancer
 - Meaning and implications of the test result etc
- May avoid screening (fear of stigma and a low perceived need)
- Affect compliance to follow-up

Psycho-social Impact of HPV Testing

(3)

Study	Setting	Result
Kwan et al 2011	Triage <ul style="list-style-type: none"> • ASCUS with reflex HPV testing 	<ul style="list-style-type: none"> • At result notification <ul style="list-style-type: none"> • HPV +ve women have significantly higher state <u>anxiety</u>, <u>cervical cancer worry</u> and <u>psychological burden</u> • At 6 months <ul style="list-style-type: none"> • Although the anxiety state and cancer worry are lowered and similar for HPV + and HPV -ve women, the <u>psychosocial burden</u> remained higher in HPV +ve women (even after colposcopy +/- treatment)
Maissi et al 2004	Triage <ul style="list-style-type: none"> • HPV testing with borderline or mildly dyskaryotic smears 	<ul style="list-style-type: none"> • HPV +ve women were more anxious, distressed, and concerned about their smear result than those with HPV -ve results, no HPV test or normal smear • Higher anxiety in <u>younger age</u>, <u>higher perceived risk of cervical cancer</u>, and reporting that they <u>did not understand the meaning of test results</u> • <u>HPV -ve was not reassuring</u> (no less anxious than those not tested)
Kitchener et al 2008 (ARTISTIC Trial)	Primary screening <ul style="list-style-type: none"> • HPV testing with cytology 	Among women with normal cytology, receiving a HPV +ve result was associated with <u>reduced Sexual Rating Scale</u> (sexual satisfaction) compared with the result-concealed group

Kitchener HC et al. The psychosocial impact of human papillomavirus testing in primary cervical screening – a study within a randomized trial. Int J Gynecol Cancer 2008;18:743-748

Kwan TC et al. Psychological burden of testing positive for high risk human papillomavirus on women with atypical cervical cytology: a prospective study. Acta Obstet Gynecol Scand 2011;90(5):445-51

Maissi E et al. A Psychological impact of human papillomavirus testing in women with borderline or mildly dyskaryotic cervical smear test results: Cross sectional questionnaire study. BMJ 2004;328:1293

What women's need and preferences

1. Women's information needs

- Different HPV viral types, transmission, implications for sexual partners, prevalence, latency and regression of HPV, their management options and the implications of infection for cancer risk and fertility
- Information to be provided before women receive the diagnosis of the infection

2. Mode of delivering HPV results

- Telephone by nurse better than letter or recall for a consultation

3. Clinician's communication style

- Normalizing HPV infection (ubiquitous nature and destigmatization)
- Providing direct responses to questions
- Making sufficient time to deal with patient's information needs and discussing management options

Intervention (1)

- Information about HPV and its clinical significance
 - Brief, simple, and correct misconceptions
 - Matched with women's need & preferences
- De-stigmatization from STD and cancer-prevention-focused
 - Kwan et al 2010 randomized Chinese women to read one of three written HPV messages:
 - Low-risk and high-risk HPVs facts (genital HPV-focused)
 - High-risk HPV facts only (cervical cancer-focused)
 - High-risk HPV facts and de-stigmatizing components:
 - Anti-stereotypical – Examples to challenge the idea that only sex workers or promiscuous people will have STD; also monogamy and practicing 'proper' sex protect a person from all potential STIs
 - Motivational - Cervical cancer prevention was explicitly stated as the goal
 - Low in complexity – low-risk HPV and genital warts were excluded to achieve maximal content simplicity.
 - Cervical cancer-focused message with specific de-stigmatizing components showed the least stigma, and were significantly less likely to believe that high-risk HPV infection implicated promiscuity, non-monogamy or that monogamy offered complete protection against high-risk HPV

Intervention (2)

- Continued education in HPV and HPV testing for frontline healthcare providers of screening
- Knowledge and attitude of healthcare providers may have a significant impact on patient care and intervention
- Survey 37 doctors and 100 nurses who provided or intended to provide direct care in cervical screening (Kwan et al 2012)
 - Most had basic knowledge of HPV and HPV vaccination
 - ~30% showed stigmatizing attitudes:
 - Individuals with HPV infection were sexually easy
 - Responsible for their infection
 - Had more than 1 sexual partner
 - Regarding HPV testing, 6 of 7 knowledge items were answered incorrectly by >50% participants

HPV Vaccination

- Information and perceptions of HPV infection not only affect cervical screening
- But also affect the perception and uptake of HPV vaccination to prevent cervical cancer
- Youth Sexuality Study survey by FPA (Li SL et al 2013):
 - Uptake rate in HK adolescent girls 7.2% (more likely born locally and have a mother with a tertiary education level)
 - Non vaccinated girls
 - Never heard of the vaccine or know little about it – 20.6%
 - HPV has little to do with me – 5.9%
 - Too early to receive the vaccine – 6.5%
 - Lack of parents' initiation and objection – 5.6%
- In HK, HPV vaccination is voluntary and the cost is borne solely by the recipient. Local adolescents rely on the financial support of their parents. Therefore, public education and medical professional's endorsement are very important to correct misconceptions, improve uptake and prevent misuse of the vaccine

Conclusions

- Women experience high levels of anxiety and negative emotional responses at all stages of cervical screening
- The negative psychosocial impact not only affects the lives of women and their families, but also the adherence to follow-up protocols to prevent cervical cancer
- Aware of the variables associated with the increased anxieties and develop interventions to alleviate them
- Information matched with women's need, de-stigmatization of HPV, reassurance, counseling, support, positive staff attitude and a well organized clinic workflow with a short waiting time are all essential in reducing women's anxiety and toward a successful cervical cancer prevention program
- Further research on the effects of various interventions such as information (content, format, timing), music, counseling etc on the QoL, psychosexual impact and compliance to follow-up