Using Research to Inform Sexuality Care for Gynecological Cancer Patients

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Flow of presentation

• Background information
  – Gynecological cancer (GC)
  – Effects of GC on sexual functioning

• Evidence-based practice (EBP) on sexuality care

• A feasibility study
  – Psycho-educational interventions (PEIs) for GC patients

• Development of a practice model on sexuality care
Background

- Gynecological cancer (GC) refers to cancer involving the female reproductive tract.

- World Health Organization (2010)
  - Cervical cancer: 3rd
  - Uterine cancer: 6th
  - Ovarian cancer: 8th

- In China, the number of cases of GC is increasing due to an expanding and aging population (Kim, Zang, Choi, Ryu, & Kim, 2009)

- In Hong Kong (HK), GC was the 3rd common cancer and the 5th leading cause of cancer death in women (Hong Kong Cancer Registry, 2014)
Background (con’t)

• A new diagnosis of GC arouses high level of uncertainty in illness, psychological distress and impaired sexual functioning among the patients (Odo & Potter, 2009; Wilmoth & Spinelli, 2000)

• According to the National Cancer Institute (2012), 50% of GC survivors suffered from long-term sexual dysfunction

• Such adverse effects do not dissipate with time and may last for a long period (Audette & Waterman, 2010; Gonçalves, 2010)

• Any adverse changes in sexual functioning may reflect problems in all areas of psychosocial aspect and quality of life (Molassiotis, Chan, Yam, & Chan, 2000; Stead, Brown, Fallowfield, & Selby, 2003)
Background (cont’d)

• Attitudes of health care professionals towards sexuality (Ekwall, Ternestedt, & Sorbe, 2003)
  – 98% thought that sexual issues should be addressed
  – Only 21% discussed sexual issues with patients

• Reasons for not discussing sexual issues
  – Feel embarrassed
  – Inadequate time
  – Lack of privacy
  – Lack of knowledge
  – Lack of resources to provide further support if needed
  – Low priority of sexuality care
  – Thinking of not their responsibility to provide such care
Background (con’t)

- **Information needs of GC patients** (Rasmusson & Thomé, 2008)
  - They wanted to get sufficient information about the sexual consequences of GC and treatment from doctors or nurses
  - Such knowledge would minimize the risk of any negative effects on a couple’s relationship

- **In Chinese culture, sexuality is viewed as a taboo topic** (Tsai et al., 2011)
  - Patients often hesitated to raise questions or concerns about sex with health care professionals
  - Women were reluctant to discuss sexual concerns with their partners
Gap of research

1. Few validated Chinese version of disease-specific sexual function instrument for clinical use
2. Unknown prevalence of sexual dysfunction in GC patients in HK
3. No consistent EBP on sexuality care
4. No guideline and practice model for implementing sexuality care for GC patients
Research journey

- Instrument translation & validation
- Concept mapping approach
- A feasibility study
- A cross-sectional study
- Systematic review
# Chinese sexual tools

<table>
<thead>
<tr>
<th>Sexual function-Vaginal changes Questionnaire (SVQ) (Chow, So, &amp; Chan, 2010)</th>
<th>Sexual Function After Gynecologic Illness Scale (SFAGIS) (Chow et al., 2013)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 core items with 7 additional items to compare pre- and post-diagnosis changes in sexual function</td>
<td>28 items</td>
</tr>
<tr>
<td><strong>5 subscales:</strong></td>
<td>Items address <strong>15 themes</strong> of sexual function</td>
</tr>
<tr>
<td>1. Intimacy</td>
<td>e.g. sexual desire, unavailability of a partner, fears about sexual activity, partner’s fears about sexual activity, sexual satisfaction, initiation of sexual activity, affectionate behavior, frequency of sexual intercourse and orgasm, vaginal dimensions and mucosal condition, potential for vaginal lubrication, intervention of the health provider, desire for sexual information, changes in sexual activity after therapy, and compliance with a prescription for a dilator</td>
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<tr>
<td>2. Global sexual satisfaction</td>
<td></td>
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<td>3. Sexual interest</td>
<td></td>
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<td>4. Vaginal changes</td>
<td></td>
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<tr>
<td>5. Sexual functioning</td>
<td></td>
</tr>
<tr>
<td>Subscale score + Single-item score, with higher scores indicating better sexual functioning</td>
<td>A total score, with high scores indicating a higher level of sexual activities and relatively freedom from sexual difficulties</td>
</tr>
<tr>
<td>Internal consistency: Cronbach’s alpha of 0.87</td>
<td>Internal consistency: Cronbach’s alpha of 0.93</td>
</tr>
<tr>
<td>Test retest reliability: 0.71-0.87</td>
<td>Test retest reliability: 0.76</td>
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<tr>
<td>Convergent and divergent validities</td>
<td>Convergent validity</td>
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<tr>
<td>Factor analysis</td>
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Assessing Sexual Function amongst Hong Kong Chinese Patients with Gynecological Cancer: Translation and Validation of the Sexual Function-Vaginal Changes Questionnaire (SVQ)

Ko Ming CHOW1
Winnie K.W. SO1,2
Carmen W.L. CHAN1,2

Objective
The study aims to translate the Sexual Function-Vaginal Changes Questionnaire (SVQ) into Chinese and to establish its psychometric properties.

Methods
A Chinese SVQ was developed by the use of the Binomial model of translation. The content validity and semantic equivalence were assessed by an expert panel. The translated version of SVQ was administered to 79 Hong Kong Chinese women who were referred from gynecological cancer to test its psychometric properties.

Results
The Chinese version of SVQ was compared to the original study for factor analysis. Internal consistency, item-to-scale correlations and test-retest reliability were high. Two convergent and divergent validities supported the Chinese SVQ to be valid.

Conclusion
We conclude that the Chinese SVQ appears to be a valid, reliable and feasible disease-specific tool for the assessment of sexual function among Chinese patients.

Key Words: Sexual function, vaginal changes, sexual function, Hong Kong Chinese.

Introduction
Gynecological cancer is now amongst the ten most common cancers in Hong Kong Chinese women1. Sexual function is generally taken to be compromised in gynecological cancer patients. However, both care and assessment in this area was very limited in Hong Kong, and, in fact, there is no validated Chinese version of a disease-specific sexual function instrument suitable for clinical use with such patients. The Sexual Function-Vaginal Changes Questionnaire (SVQ)2,3 is a short self-assessment questionnaire recently developed to assess sexual and vaginal problems in gynecological cancer patients. The original assessment found the English version of SVQ to be a valid and reliable instrument4,5.

This study aimed to translate the SVQ into Chinese and to establish its psychometric properties among Hong Kong Chinese women suffering from gynecological cancer. The completion time, understanding and acceptance of the questionnaire were also assessed.

Support for this research was provided by the Hong Kong Research Grants Council, Project No. 8521026 and the University Grants Committee, Project No. 9620064. The data related to the patients were collected by the gynecological surgeons at Queen Mary Hospital and The Chinese University of Hong Kong.

Keywords: Sexual function, gynecological cancer, Hong Kong Chinese.

Psychometric properties of the Chinese version of Sexual Function after Gynecologic Illness Scale (SFAGIS)


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Abstract
Purpose This study aims to develop the Chinese version of the Sexual Function after Gynecologic Illness Scale (SFAGIS) and to establish its psychometric properties in Hong Kong Chinese patients with gynecological cancer.

Methods A Chinese version of SFAGIS was developed using the Binomial model of translation and guidelines for cross-cultural adaptation of scales. The content validity and semantic equivalence were assessed by an expert panel. The translated version of SFAGIS was administered to 150 Hong Kong Chinese women with gynecological cancer to test the scale’s psychometric properties and to assess its feasibility.

The convergent validity of the Chinese scale was tested by correlating it with the Chinese version of the sex relations subscale of the Psychosocial Adjustment to Illness Scale Self-Report (PAS-SR).

Results
The average completion time for the Chinese SFAGIS was 13.5 ± 6.4 min. The internal consistency of the Chinese SFAGIS was 0.95. Test-retest reliability was also high with an inter-class correlation coefficient of 0.76. A pleasure product-constraint correlation found strong correlations among the Chinese SFAGIS and the Chinese version of the sex relations subscale of the PAS-SR, indicating that both scales measure the same construct to a similar degree.

Conclusions The Chinese version of SFAGIS is a reliable and valid instrument which can be used in clinical practice and research for assessing sexual function problems in Chinese patients with gynecological cancer and to identify those in need of attention.

Keywords: Sexual function after Gynecologic Illness Scale, Sexual function-gynecological cancer, Hong Kong Chinese.
Prevalence of sexual dysfunction

• A convenience sample of 225 HK Chinese GC survivors
  – Uterine cancer (n = 84, 37.3%)
  – Cervical cancer (n = 74, 32.9%)
  – Ovarian cancer (n = 58, 25.8%)
  – Others (n = 9, 4%)

• Age ranged from 21 to >60
  – Most in the 46 to 55 age group (n = 96)

• 76.4% were married or with regular sexual partner, but only 50.6% were sexually active in the past 1 month

• Stage of cancer: 69.8% Stage I
Prevalence of sexual dysfunction (cont’d)

• Treatment modalities
  – Surgery alone (55.6%)
  – Surgery plus adjunctive therapy (41.7%)
  – Chemotherapy alone (1.8%)
  – Radiotherapy alone (0.9%)

• 62.2% had completed cancer treatment for more than 6 month
  44.4% had completed cancer treatment for more than 1 year

• 86.7% had undergone hysterectomy
Prevalence of sexual dysfunction (cont’d)

• **SVQ**
  - Subscale scores
    • Below-median mean scores in intimacy and sexual interests
  - Single-item scores
    • Most affected aspects of sexual function in all participants were reduced interest in sex and close physical contact
    • For sexually active participants, the most encountered sexual problems were difficulty in reaching orgasm, reduced vaginal lubrication and not feeling relaxed after having sex
    • When compared with pre-diagnosis, the most deteriorated sexual function was reduced vaginal lubrication, followed by dyspareunia and reduced sexual interest

• **SFAGIS**
  - Mean total score: 41.0 (SD = 23.8)
Prevalence of sexual dysfunction (cont’d)

• Overall, GC patients experienced sexual dysfunction after diagnosis and treatment for the disease

• Implications for practice
  – Sexual assessment should be incorporated into routine practice for identification of sexual problems
  – Appropriate sexuality care should be developed and provided to minimize the severity of sexual problems
Evidence-based practice (EBP) on sexuality care

• EBP is the integration of the best available research evidence to produce best practice or guideline that is most likely to contribute to positive outcomes for clients (Hickey, 2000; McEwan & Wills, 2011; Pearson, 2003)

• Psycho-educational interventions (PEIs) have received more attention in cancer care rehabilitation over recent decades

• Theory of Uncertainty in Illness provides the philosophical underpinning for the interventions (Mishel & Braden, 1988)
Systematic review

• PEIs
  – Effective in treating depressive symptoms among GC patients (standardized mean difference = -0.80; 95% confidence interval, -1.05 to -0.54)
  – Information provision significantly improved the mental aspect of quality of life (standardized mean difference = -0.41; 95% confidence interval, -0.74 to -0.08)
  – Appeared to improve sexual functioning among GC patients

(Chow, Chan, Choi, & Chan, 2016)
Systematic review (cont’d)

<table>
<thead>
<tr>
<th>Effective design of PEIs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>3 main components</strong></td>
<td>Information provision, behavior therapy &amp; psychological support</td>
</tr>
<tr>
<td><strong>Format</strong></td>
<td>Individual or group-based, with or without couple participation</td>
</tr>
<tr>
<td><strong>Provider</strong></td>
<td>Nurse</td>
</tr>
<tr>
<td><strong>Provision time frame</strong></td>
<td>Before the start of cancer treatment &amp; continued after discharge</td>
</tr>
<tr>
<td><strong>Number of session</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>Duration of each session</strong></td>
<td>30-60 minutes</td>
</tr>
</tbody>
</table>

**Key Words**
- Gynecological cancer patients
- Psychoeducational interventions
- Psychological outcomes
- Quality of life
- Sexual functioning
- Systematic review

**Background:** Psychoeducational interventions are recommended for use with clinical gynecological cancer patients to improve their patient care outcomes. However, the evidence of their effectiveness is far from conclusive. **Objective:** The objective of this study was to identify the best available research evidence related to the effects of psychoeducational interventions on sexual functioning, quality of life, and psychological outcomes in gynecological cancer patients. **Methods:** A systematic search was conducted to identify English and Chinese articles from the inception of the databases to April 2012 and included 13 English databases and 7 Chinese databases. Gray literature or unpublished studies were also searched. **Results:** A total of 11 studies involving 973 gynecological cancer patients were included in the review. Meta-analysis results for 4 comparable studies indicated that psychoeducational interventions were effective in reducing depressive symptoms among gynecological cancer patients (standardized mean difference = −0.80; 95% confidence interval, −1.05 to −0.54), whereas information provision significantly improved the mental aspect of quality of life (standardized mean difference = −0.41; 95% confidence interval, −0.74 to −0.08). With regard to sexual functioning, psychoeducational interventions appeared to have benefits in improving the sexual life.
A feasibility study

• Aims
  1. To test the feasibility of implementing an evidence-based PEI programme for GC patients
  2. To assess the preliminary effects of the programme on uncertainty, anxiety and sexual functioning

• Design
  – Single-blinded RCT
  – Mixed method design

• Samples
  – Newly diagnosed GC patients with surgery as the first-line treatment
  – Over 18 years old
  – Able to understand spoken Cantonese and read Chinese

(Chow, Chan, Chan, Choi, & Siu, 2014)
## A feasibility study (cont’d)

### PEI programme – 1st session

<table>
<thead>
<tr>
<th>Components</th>
<th>Information provision &amp; psychological support</th>
</tr>
</thead>
</table>
| **Content** | - What is gynecological cancer  
- Causes of gynecological cancer  
- Treatment for the disease and side effects  
- Impacts of related treatment on body image, sexuality & childbirth  
- Psychological reactions to the illness  
- Communications with family & friends  
- Feelings expression & reassurance |
| **Format** | Individual |
| **Provider** | Nurse |
| **Provision time** | Before the start of cancer treatment |
| **Length of session** | 45 – 60 minutes |
## A feasibility study (cont’d)

<table>
<thead>
<tr>
<th>PEI programme – 2(^{nd}) session</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Components</strong></td>
<td>Information provision, behavior therapy &amp; psychological support</td>
</tr>
</tbody>
</table>
| **Content** | - Post-operative care e.g. wound management, dietary advice  
- Reminder of follow-up schedule  
- Behavior therapy e.g. relaxation breathing exercises & coping skills  
- Feelings expression & reassurance |
| **Format** | Individual |
| **Provider** | Nurse |
| **Provision time** | After operation & during the in-hospital period |
| **Length of session** | 30 – 45 minutes |
A feasibility study (cont’d)

<table>
<thead>
<tr>
<th>PEI programme – 3rd session</th>
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<tbody>
<tr>
<td><strong>Components</strong></td>
</tr>
<tr>
<td>Information provision &amp; psychological support</td>
</tr>
<tr>
<td><strong>Content</strong></td>
</tr>
<tr>
<td>- Problems or issues encountered after discharge such as vaginal bleeding and wound condition</td>
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<tr>
<td>- Advice &amp; management on the issues arisen</td>
</tr>
<tr>
<td>- Provision of encouragement</td>
</tr>
<tr>
<td><strong>Format</strong></td>
</tr>
<tr>
<td>Individual over telephone</td>
</tr>
<tr>
<td><strong>Provider</strong></td>
</tr>
<tr>
<td>Nurse</td>
</tr>
<tr>
<td><strong>Provision time</strong></td>
</tr>
<tr>
<td>4 weeks after operation &amp; discharged home</td>
</tr>
<tr>
<td><strong>Length of session</strong></td>
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<tr>
<td>30 minutes</td>
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</table>
## A feasibility study (cont’d)

### PEI programme – 4th session

<table>
<thead>
<tr>
<th>Components</th>
<th>Information provision &amp; psychological support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content</strong></td>
<td></td>
</tr>
<tr>
<td>- Sexuality</td>
<td></td>
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<tr>
<td>- Communication skills</td>
<td></td>
</tr>
<tr>
<td>- Social support networks</td>
<td></td>
</tr>
<tr>
<td>- Available support groups &amp; resources</td>
<td></td>
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<tr>
<td>- Social role changes e.g. returning to work</td>
<td></td>
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<tr>
<td>- Financial impact</td>
<td></td>
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<tr>
<td>- Feelings expression &amp; support from other people in similar situations</td>
<td></td>
</tr>
<tr>
<td><strong>Format</strong></td>
<td>Group</td>
</tr>
<tr>
<td><strong>Provider</strong></td>
<td>Nurse</td>
</tr>
<tr>
<td><strong>Provision time</strong></td>
<td>8 weeks after operation</td>
</tr>
<tr>
<td><strong>Length of session</strong></td>
<td>60 minutes</td>
</tr>
</tbody>
</table>
A feasibility study (cont’d)

- A total of 26 participants
  - 13 uterine cancer
  - 7 ovarian cancer
  - 6 cervical cancer
- Mean age: 54.5 years
- Stage of cancer: 73.1% stage I
- Outcome measurement at 3 time points
  - T0: Baseline
  - T1: After operation & during in-hospital period
  - T2: On completion of the PEI programme
Quantitative results

• Between-group changes
  – A statistically significant improvement in the level of inconsistent information about the illness within the category of uncertainty in the intervention group at T1 (p=0.026)
  – No significant difference was found in anxiety and sexual functioning

• Within-group changes
  – The intervention group demonstrated a better trend for improvement than the attention control group in overall uncertainty
Qualitative data

• Provide informational support
  – Acquiring knowledge of the disease and related treatment
  – Felt less anxious and stressful

• Offer emotional support
  – Offering psychological support
  – Removing worries about future sexual life
  – More confident in managing the disease during the rehabilitative period

• Appropriate programme design

• Positive feelings towards the intervention
Concept mapping approach

• To address the knowledge gaps in understanding nurses’ and GC patients’ concerns about sexual functioning and sexuality care

• To identify ground-breaking information
  – What unmet supportive needs in the sexuality area exist among Hong Kong Chinese GC patients
  – How to handle barriers and deliver the right kind of care to them in a practical, feasible and acceptable way

• To develop a practice model to guide and promote the provision of sexuality nursing care to Hong Kong GC patients
Concept mapping approach

**Phase I**
- A qualitative method
- To explore and elicit perceptions of sexual functioning and ideas about good nursing practice in sexuality care
  - GC patients
  - Their spouses/partners
  - Registered nurses
  - Physicians

**Phase II**
- Same participants rate the perceived importance as to how the statements generated in Phase I will affect
  - Acceptability
  - Appropriateness
  - Feasibility of providing sexuality care
- A concept map illustrating the relationships and clustering between the statements

**Phase III**
- The concept map will be used to inform the development of a practice model and local protocol
- To guide nurses and promote the provision of timely, effective and economical nursing care in the area of sexuality
Phase I: Qualitative entity

• Step 1: Literature review
  – To extract themes and statements pertinent to the factors affecting the acceptability and provision of sexuality care for GC patients

• Step 2: Qualitative interviews
  – Recruit 30 GC patients, 30 spouses/partners, 20 registered nurses and physicians
Qualitative interview

• Individual interview lasts for 30-40 minutes

• A broad statement
  – “Many patients with GC are concerned about sexuality and we would like to hear from you about your own perceptions and experiences in the area of sexuality and sexuality care, the scope/content of such care, any concerns you might have, and your views regarding the use/provision of sexuality care by nurses”

• Appropriate prompts
  – ‘How are these two ideas related?’
Phase II: Quantitative entity

• All participants in Phase I will be contacted again
  – To rank the importance of each statement generated on a seven-point Likert scale
    • 1 = least important to 7 = most important

• Quantitative data will be entered into the concept mapping software for multi-dimensional scaling and cluster analysis
  – To group individual statements on the map into clusters of statements
  – To reach a better understanding of the relationship between the statements
Phase III: Application of the concept map

• Transform the results into
  1. A practice model guiding and promoting the provision of sexuality care for GC patients and their spouses/partners
  2. To inform the development of a local protocol of sexuality nursing care to support GC women and their spouses/partners
  3. To produce clinical indicators to measure practice standards

• The newly-developed protocol will be returned to the participants in Phases I and II for further validation by means of Likert scales
  – ‘very appropriate/acceptable’ to ‘very inappropriate/unacceptable’
Conclusion

- Translating and integrating research to nursing care can inform the development of advanced nursing practice to address the rapid technologic advances and resulting sophisticated treatment
- Allow standardization of nursing care
- Bridge the theory-practice gap
References


References (cont’d)


Thank you!