How Clinicians Can Create High-Quality Research Questions in Sexual Medicine

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Vancouver, Canada (Coast Salish traditional territory)

1. Deriving research questions from clinical experience

2. Developing registries/biobanks to address these questions

3. Identifying a sustainable research niche

4. Multidisciplinary collaboration to foster impactful and translational research

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Deriving research questions in the clinic

Type of experience

Seeing rare/unique case(s)

 Identifying unanswered question(s) in the clinic

 Years of experience seeing a disease/condition/ symptom

Research

Case report/series

Retrospective/Prospective cohort

 Cohort or Clinical trial – ensure correct study design

Rare/unique case(s)

CLINICAL CONUNDRUM

Clinical Conundrum: A 33-Year-Old With Pain Post-Orgasm and a History of Endometriosis

Rare/unique case(s)

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Pain with orgasm in endometriosis: potential etiologic factors and clinical correlates

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Unanswered questions

Why does deep dyspareunia occur in endometriosis?

Clinical experience and study design

Clinical experience and study design

• Green: endo

Red: nerve fibres

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Registry and Biobank

Endometriosis and Pelvic Pain Interdisciplinary Cohort (EPPIC)

Endometriosis Determinants of Oncogenesis (ENDOONC)

- Key facilitators:
 - Buy in from clinical colleagues and administrators
 - In kind support from established researchers and existing resources
 - Initial seed funds











Registry and Biobank

Endometriosis and Pelvic Pain Interdisciplinary Cohort (EPPIC)

- Integrated with clinical processes: all new referrals complete baseline questionnaires online
- <u>Consent</u> obtained to use data for clinical only or for both clinical + research (85%)
- Physical examination and surgical data collected with standardized form
- Follow-up questionnaires annually (need reminders/incentives)

Registry and Biobank

- Endometriosis Determinants of Oncogenesis (ENDOONC)
- <u>Integrated with clinical processes</u>: all samples are stored in pathology archive
- Annotation: stored samples are annotated
- Consent obtained for prospective collection of high value samples (e.g. for studies requiring fresh tissue and for primary cell culture)
- <u>Linkage:</u> To baseline questionnaires, physical examination and surgical data, and to follow-up questionnaires in the registry

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Finding a research niche

Based on research environment

- What gap exists in:
 - Institution (hospital, university, research institute)
 - State/province
 - National
 - International
- Matching to existing priorities:
 - Institution
 - Funding agencies

Based on knowledge/skillset

- Clinical practice: knowledge of disease/condition and access to patients
- Surgical practice: access to human samples
- Existing or new research skill:
 - Statistics/epidemiology
 - Clinical trials
 - Other skills to study human subjects or derived tissues/cells

Finding a research niche

Based on research environment

- <u>Filled gap</u> in endometriosis research at institution/province
- <u>Joined</u> the Women's Health Research Institute (WHRI) with its aligned priorities
- Oriented research to peer review committee(s) of the Canadian Institutes of Health Research (CIHR)

Based on knowledge/skillset

- Knowledge of endometriosis
- Access to patients and surgical samples
- <u>Previous</u> research training in statistics
- New research training in pain assessment (e.g. QST)

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Multidisciplinary collaboration

- Qualitative methods
- Statistics/Epidemiology
- Al/Machine learning
- Pain neurophysiology
- Basic lab science









Multidisciplinary collaboration

Goal

- Be a good collaborator
- Be a professional
- Be a good colleague
- Be friendly
- Be generous
- Be passionate
- Be visionary

Examples

- Share your expertise
- Discuss authorship early
- Give & take
- Attend local/int'l conferences
- Volunteer for committees, etc.
- (Co)-lead the research
- Provide the big picture

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Patient oriented research

Patient research partners

- Arises from good clinical care
- Can be involved in:
 - Study conception
 - Study design
 - Knowledge translation
 - Peer researchers
- Utilize best practices (e.g. diversity, renumeration)

Knowledge translation (KT)

 Disseminating research to the public (e.g. public events, website, social media)

 Liaise with foundations and leverage KT for philanthropy

Art gallery

Photovoice

Digital storytelling

(Shared with consent on Pelvicpainendo.ca)

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Thank you!

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- BCwomens.ca/our-services/gynecology/pelvic-pain-endometriosis

