

35th European Cystic Fibrosis Conference
6 – 9 June, 2012

**Finding Collaborators, Working across
Many Sites: Lessons from the
Menopause Study**

Anna Tsang RN MSN NP CDE
Adult CF Program, St. Michael's
Hospital, /University of Toronto,
Toronto, Ontario, Canada

Background

- Approximately 3850 people with CF in Canada
- 42 CF clinics
 - Pediatric – 18
 - Adult – 17
 - Pediatric + Adult – 7
- Total of \approx 40 nurse coordinators
- **Canadian CF Nurses Interest Group (CCFNIG)**
- Meets once or twice a year
 - CF annual general meeting (april)
 - NACFC (Oct./Nov.)

Canadian CF Nurses Interest Group CCFNIG

- Build collegial Relationship and friendships
- Excellent network throughout the year via e-mail or phone
- Sharing knowledge, experience, expertise by presenting information, case studies, special teaching tools and forms at our yearly or bi-yearly meetings
- Provide a safe environment to share frustrations and concerns and ideas
- Provided a **forum** for research ideas and projects!!

Nursing Research

- **A process:**

Validates, refines existing knowledge

Generate new knowledge that influence our practice directly or indirectly.

Essential for quality improvement

- **History:**

Research as at the beginning of nursing profession

Florence Nightingale: In 1895, analysis soldiers morbidity and mortality data during the Crimean War

Burns, N & Grove, s. Understanding Nursing Research. 1995

Journey of the menopause study

- April 2005 – CCFNIG meeting
- Two Nurse Coordinators from Victoria BC, Canada – presented a talk on Menopause
- Sharon Wiltse (Adult) & June Jacobs (Peds)
- Everyone agreed: CF women will be facing perimenopause symptoms or menopause due to improved survival!!

Journey of the Menopause Study

Questions???

- When do they start?
- Would they have the same symptoms?
- Would symptoms of perimenopause/ menopause complicates CF or their ability to cope/deal with their CF and the symptoms?
- Would it worsen respiratory status?
- How can we help?? – We need more information!!

Study worth doing

- Increase knowledge about health issues re: aging CF women
- It will change our practice!
- Provide education and appropriate interventions to help CF women through their change of life
- Make early referrals for specialist i.e. Women's health clinic, psychiatry

More questions?

- How many women with CF is of age?
- Who should take the lead?

- Conclusion:

There should be enough number of women with CF to recruit – gives power to the study!

Someone to write the protocol and circulate it for input and comments

Someone to get started!

Journey Begins!!

Sharing:

- Sharon (BC) gave me a book on menopause to get started
- Reviewing literature re: menopause general population
- Menopause Rating Scale
- Borrow literature re: Asthmatic symptoms changes during menstrual cycles.
- Found only one article on CF by Maria Johannesson
- Rough draft sent to all nurse coordinators for review in 2006

Report Progress at Every Meeting

Communication

NACFC- Oct. 2005

- Brief review of literature findings
- Purpose, type of study, method for data collection i.e. CF related questionnaire and Menopause Rating Scale
- Future implications – how it may change practice.

CCFNIG – April 2006

- Presenting first rough draft of protocol
- Collect input from group
- Explore possible **funding** source! for printing, time, pay assistant etc.

NACFC – Oct. 2006

- Developing a set of questionnaire: clinical information, unique respiratory symptom, menstrual history and medication i.e. hormone, herbal medications and inhaled steroid
- More talk about **funding!**
- Finally set a **time line!**
 - Sent all for input by Nov. 06
 - Complete final draft by Jan. 07
 - Submit to Research Ethic Board (REB) by april 07
 - Collecting data by asap after REB approval
 - NO timeline for other sites!**

Reality Hits!!

- **Timeline** was not realistic!
- Utilizing resource available to complete a protocol with potential to go through REB needs time
- Took from Oct., 2006 to Dec. 2007 to REB submission

Mobilizing Resource

- MD/PhD (Dr. Anne Stephenson) to review protocol and questionnaires
- Research coordinator:
 - Patient Information Letter:
 - Nature of study,
 - Voluntary participation
 - Implied consent if answer questions and anonymity
 - Name/ phone number of contact person if question or concerns (Do No Harm!)
- Program manager: support cost of printing
- Volunteer: to help with data collection

Initial Success

- Study approved by REB, april 2008 (3 yrs. Later) with the intention to be a multi-center nursing study.
- St. Michael' s site as a primary site and all data will be forward to SMH for final analysis.
- Data collection started immediately.
- Final Protocol/documents sent out to all nurse coordinators of Adult CF Programs to go through their own REB.

Impact of lack of funding support

- Questionnaires required professional translation and must be matched word for word. (estimated cost was \$3000 to \$4000 CAD)
- Forced to exclude the French speaking sites.
- Lost four major adult centers and four Peds/Adult combined centers from Quebec!

Losing Momentum!

- No more communication via e-mail once approved protocol and necessary document of sent out to all other sites.
- Too busy to collect data and did not communicate as often as before!
- St. Michael's Hospital became the only site completed the study.
- Final data was presented at CCFNIG meeting, in Oct. 2009-NACFC Our study was accepted for poster presentation at NACFC 2009

Lessons learned

- Completion of our Study validates having a **forum** i.e. CCFNIG or any nursing group meets regularly is a great place to start
- Uniting a group of experts with common goal = brain power!
- Nursing research **brings new knowledge** and **improve practice.**
- Nursing research may lead to other scientific research that may further benefit our patients.

Lessons learned

- Study led by a **working group** instead of **one person/site**
- **Maintain communication** regularly via meetings, e-mail or Sykes frequently to prevent loss of momentum
- **MUST obtain funding** as a group or individually!!!
- Research study involving populations with **different languages can be challenging**
 - Remote data collection – addendum in REB document
 - Cooperation from local research coordinator or nurse coordinator

Lesson Learned

- **Involve nurse administrators** and nursing research director will help gain financial support or protective time.
- **Utilize all resources** within or outside of your institution if possible!!

Conclusion

- Our menopause research study would not have been completed without the effort and encouragement from all CF nurse coordinators in Canada

Gained New Knowledge

The result of our study demonstrated that women with CF develop perimenopause symptoms and menopause, **three year** sooner than women in general population.
(N=33)

- Data showed us that of all perimenopausal symptoms sleep disturbance is predominant and most severe. Anxiety and depressive symptoms are second.

Conclusion

Changed Practice:

- The information from the study influence my daily practice in assessing and educating women of age and early referral for CF women reaching menopause.

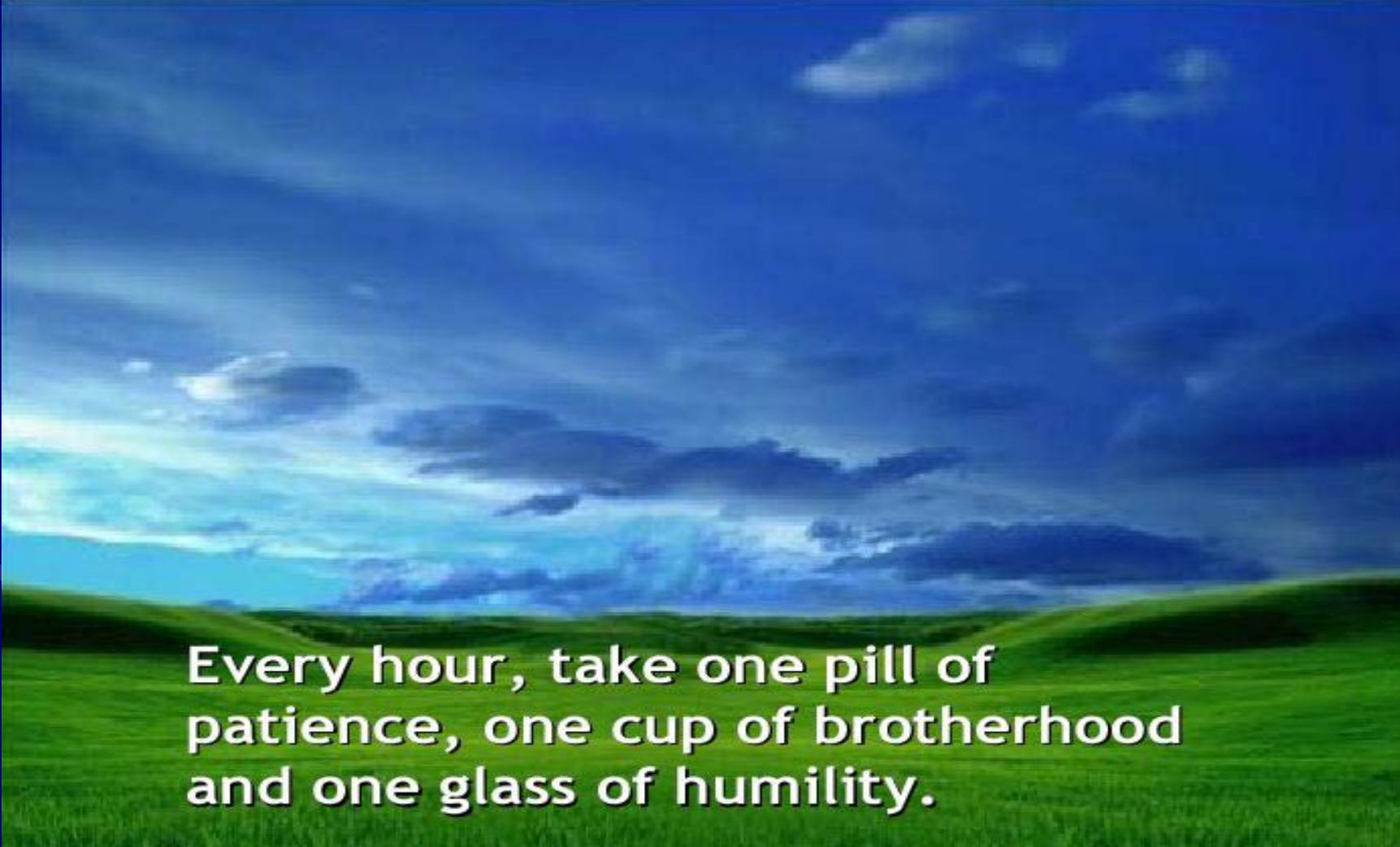
Generated new research idea:

- Findings led to another study measuring ovarian reserve in women with CF.

Installed confidence:

- Currently working on new research protocol with another program within the hospital

Personal Suggestion

A landscape photograph showing rolling green hills under a dramatic, cloudy sky. The sky is filled with dark, heavy clouds, with some lighter patches where the sun is breaking through. The hills are lush green and stretch across the horizon. The overall mood is serene yet powerful.

Every hour, take one pill of
patience, one cup of brotherhood
and one glass of humility.

Acknowledgement:

Special thanks to Sharon Wiltze & June Jacob and
all my colleagues in the Canadian CF Nurses
Interest Group

- **Thank you**
- **Go for it!!**

