Building Successful International Research Collaborations

Anna Strömberg, RN, PhD, NFESC, FAAN

Professor, Linköping University, Sweden

Visiting professor University of California Irvine,

Adjunct professor University of Southern Denmark, Odense
Linköping

- Population: 152,777
- Fifth largest city in Sweden
- Linköping university founded in 1975
- 27,600 students
  - 80% undergraduate, 20% master level
- 3,800 employees
Sweden

• Population: 9.5 million
• Area: 174,000 mile²
• BNP per capita GDP: 40,000 USD
• Latitude: 58°24′39″ N
• Longitude: 15°37′17″ E

California

• Population: 39 million
• Area: 164,000 mile²
• BNP per capita GDP: 46,000 USD
• Latitude: 34°03′08″ N
• Longitude: 118°14′37″ W
International collaboration: Why?

Learning from NASA
Parallels NASA and Cardiovascular Nursing Research

- Addressing global challenges
- Addressing large issues, important for mankind
- Are constantly in need of experts and experience
- Have ‘funding issues’
International collaboration
Cardiovascular Nursing Research

• Leverages power of diversity of ideas
  – New ideas, new approaches from other countries/cultures
• Leverages investment in capabilities and technologies
  – New students, mentors, methods
• Leads missions and approaches otherwise not possible
  – Multicenter studies
  – Addressing global challenges
  – Expanded funding resources
My Research Program

• Self-care in long-term illness (cardiovascular)
  – Theory development
  – Instrument development
  – Interventional studies evaluating technology to support self-care
Middle Range Theory of Self-Care of Chronic Illness

Riegel, Jaarsma, Strömberg, 2012
A Middle-Range Theory of Self-Care of Chronic Illness

Barbara Riegel, DNSc, RN, FAAN, FAHA;
Tiny Jaarsma, PhD, RN, FAAN, FAHA, NFESC;
Anna Strömberg, PhD, RN, FAAN, NFESC

Nearly 50% of adults have one or more chronic illnesses. Self-care is considered essential in the management of chronic illness, but the elements of self-care in this context have not been specified in a middle-range theory. This article describes a middle-range theory of self-care that addresses the process of maintaining health with health promoting practices within the context of the management required of a chronic illness. The key concepts include self-care maintenance, self-care monitoring, and self-care management. Assumptions and propositions of the theory are specified. Factors influencing self-care including experience, skill, motivation, culture, confidence, habits, function, cognition, support from others, and access to care are described. Key words: chronic illness, middle-range theory, self-care
Development and testing of the European Heart Failure Self-care Behaviour scale

Heart failure related self care behaviour reflects the behaviour that a HF patient undertakes to maintain life, healthy functioning, and well being. This definition includes behaviours like adherence to medication, diet and exercise, as well as self-management of symptoms, but it also refers to behaviours such as daily weighing to assess fluid retention and seeking assistance when symptoms occur. To evaluate the effectiveness of interventions aiming at improving self-care it is important to know if and how patients changed their self-care behaviour as a result of such interventions. Identification of deficits in HF specific behaviours can help health care professionals improve patient education or support behavioural change.

To evaluate effectiveness of interventions on self care behaviours of HF patients we developed a valid, reliable and user-friendly scale, The European Heart Failure Self-Care Behviour Scale.

The European Heart Failure Self-Care Behaviour Scale (EHFScB scale) comprised of items rated on a 5-point scale between 1 (I completely agree) and 5 (I completely disagree) was published in 2003. Currently a 12-item and 9 item version of the EHFScB scale. The scale is considered easy to administer and practical to use.

The EHFScB scale is available in several languages

Page manager: tiny.jaarsma@liu.se
Last updated: 2014-10-30
Versions

The EHFScB scale is available in several languages. Please check if your language is available. If you do not see your language, please feel free to translate the scale.

The following procedure should be followed

1. You find someone to translate the English scale into the new language (native speaker)
2. You find another person to translate the scale back from that the new language version to English
3. You send me that English version and the new language version and I will check the English version. If we agree at a final version we can declare it an official version and possibly upload your version to this site

The scale is available in the following languages

Brazilian-Portuguese (pdf)
Castellano (pdf)
Catalan (pdf)
Chinese (pdf)
Danish 12 items (pdf)
Danish 9 items (pdf)
Dutch (pdf)
English 12 items (pdf)
English 9 items (pdf)
Finnish (pdf)
French 12 items (pdf)
German (pdf)
Greek 9 items (pdf)
Hebrew (pdf)
Icelandic 9 items (pdf)
Italian (pdf)
Japanese (pdf)
Korean (pdf)
Lithuanian (pdf)
Persian 12 items (pdf)
Persian 12 items, 2nd option (pdf)
Persian 9 items (pdf)
Polish 9 Items (pdf)
Polish 12 Items (pdf)
Portuguese 12 items (pdf)
Russian 9 Items (pdf)
Swedish (pdf)
Turkish (pdf)
Vietnamese (pdf)
Table 1: The European Heart Failure Self-care Behaviour Scale: Hebrew version

<table>
<thead>
<tr>
<th>מספר המסר</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. אני שוקל את עצמי כל יום</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. אם יש לי קוצר נשימה אני גה/ה</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. אם קוצר נשימה쉴 מהנה אני מתחבר/ת לרופאים או לאדהות המבקרים</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. אם נגיפים נפוחות יחר מזרחי אני מתחבר/ת</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Self Management

Comparison of self-care behaviors of heart failure patients in 15 countries worldwide

Tiny Jaarsma\textsuperscript{a,*}, Anna Strömberg\textsuperscript{b,c}, Tuvia Ben Gal\textsuperscript{d}, Jan Cameron\textsuperscript{e}, Andrea Driscoll\textsuperscript{f}, Hans-Dirk Duengen\textsuperscript{g}, Simone Inkrot\textsuperscript{g}, Tsuey-Yuan Huang\textsuperscript{q}, Nguyen Ngoc Huyen\textsuperscript{m}, Naoko Kato\textsuperscript{h}, Stefan Köberich\textsuperscript{i,j}, Josep Lupón\textsuperscript{k}, Debra K. Moser\textsuperscript{l}, Giovanni Pulignan\textsuperscript{n}, Eneida Rejane Rabelo\textsuperscript{o}, Jom Suwanno\textsuperscript{p}, David R. Thompson\textsuperscript{e}, Ercole Vellone\textsuperscript{r}, Rosaria Alvaro\textsuperscript{r}, Doris Yu\textsuperscript{s}, Barbara Riegel\textsuperscript{t}

\textsuperscript{a} Department of Social and Welfare Studies, Linköping University, Linköping, Sweden
\textsuperscript{b} Department of Medicine and Health Sciences, Linköping University, Linköping, Sweden
\textsuperscript{c} Department of Cardiology, County Council of Östergötland, Linköping, Sweden
\textsuperscript{d} Heart Failure Unit, Rabin Medical Center, Petah Tikva, Affiliated to the Sackler Faculty of Medicine, Tel Aviv University, Israel
\textsuperscript{e} Cardiovascular Research Centre, Australian Catholic University, Melbourne, Australia
\textsuperscript{f} School of Nursing and Midwifery, Deakin University, Melbourne, Australia
\textsuperscript{g} Department of Cardiology, Charité University Hospital, Berlin, Germany
\textsuperscript{h} Department of Cardiovascular Medicine, The University of Tokyo Graduate School of Medicine, Tokyo, Japan
\textsuperscript{i} Department of Cardiology & Angiology I, University Heart Center Freiburg-Bad Krozingen, Freiburg, Germany
\textsuperscript{j} Department of Nursing Science, Charité - Universitätsmedizin Berlin, Germany
\textsuperscript{k} Unitat d'Insuficiència Cardíaca, Hospital Universitari Germans Trias i Pujol, Badalona, Spain
\textsuperscript{l} Department of Cardiology, Charité - Universitätsmedizin Berlin, Germany
\textsuperscript{m} Department of Cardiology, Hanoi Heart Hospital, Hanoi, Vietnam
\textsuperscript{n} Department of Cardiology, St. Vincent’s University Hospital, Dublin, Ireland
\textsuperscript{o} Department of Cardiology, Hospital Universitari Germans Trias i Pujol, Badalona, Spain
"
Self-care around the world:
% low self care in exercise in Heart Failure patients

- Italy2
- Brazil
- Hongkong
- Sweden2
- US Mex South West
- Taiwan
- US South East
- Spain
- Sweden3
- Sweden1
- Israel
- Italy1
- Japan
- Thailand
- Serbia
- Australia2
- Australia1
- Netherlands
- US North East
- Vietnam
- Germany1
- Germany2
Nordforsk project 2015-2018

Symptom monitoring after hospitalisation in patients with advanced heart failure – A Nordic-Baltic study
One hour before delivering the application……..
Aim and Design

To determine the effect on HF readmissions of monitoring HF symptoms combining self-assessment tools and a non-invasive monitoring device.

- Discharge
- 30 days daily symptom monitoring intervention at home
- 30 d after discharge
- 3, 6 m after discharge
Study phases

1. Testing device, interview feasibility (n=10)
2. RCT pilot with sham (10+10+10)
3. Developing treatment algorithm
4. RCT (100+100+100)
Nordic-Baltic study added value

• Building
  – Knowledge
  – Competence across countries: Norway, Sweden and Lithuania
  – Career development, mentorship, supervision of 2 PhD students
  – Networks
  – Friendship
Exergaming in cardiac patients:

”Yes Wii can!!!”

What is Exergaming?
From Active Play Games to Health Outcomes

Game playing $\rightarrow$ Improved mediating factors $\rightarrow$ Improved outcomes

- Active play games
  - Challenge
  - Motivation
  - Role models
  - Performance
  - Feedback
  - Enjoyment

- Self-concepts

- Self-efficacy

- Physical skills, fitness, & well-being

- Communication & social support

- Better health behaviors
  - More workouts
  - New habits
  - Adherence
  - Increases in active game play and other physical activities

- Better health & Lower healthcare costs

Lieberman DA et al circulation 2011
Exergaming to improve exercise

Nintendo Wii

Bowling

Boxing
Nintendo Wii

Tennis

Baseball

Golf
Heart rate and exergames

Fig. 2

Variability in heart rate (HR) for participants at rest and during play on all video games

Taylor 2012
Pilot HF-Wii study

Exergaming to improve physical activity in persons with heart failure

The aims were to evaluate:
1. Feasibility of the study protocol
2. Adherence to Wii gaming
3. Effects of Wii on exercise capacity and daily physical activity
Pilot HF-Wii study (n=32)

<table>
<thead>
<tr>
<th><strong>Age</strong></th>
<th>63 (±14)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Female Sex</strong></td>
<td>10 (32%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>- Above high school</td>
<td>18 (57%)</td>
</tr>
<tr>
<td><strong>Marital state</strong></td>
<td></td>
</tr>
<tr>
<td>- Married/relationship</td>
<td>26 (84%)</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td>28 (90%)</td>
</tr>
<tr>
<td><strong>Grandchildren</strong></td>
<td>23 (74%)</td>
</tr>
<tr>
<td><strong>New York Heart Association class (NYHA)</strong></td>
<td></td>
</tr>
<tr>
<td>- NYHA II</td>
<td>21 (68%)</td>
</tr>
<tr>
<td>- NYHA III</td>
<td>9 (29%)</td>
</tr>
</tbody>
</table>
Introduction session in hospital

Installation at home

Safety Guidelines

Saposnik G et al, 2010, Stroke
Good adherence to playing advice

**Time playing on the Wii**

- the mean time exergaming was 28 (±13) min.
Results Pilot study

- Safe and feasible
- Exercise capacity (6MWT) increased in 52% of the patients after 3 months
Factors related to minutes playing on the Wii

<table>
<thead>
<tr>
<th></th>
<th>↓ minutes exergaming</th>
<th>↑ minutes exergaming</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=15</td>
<td>N=15</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>14 (93%)</td>
<td>14 (93%)</td>
<td>.334</td>
</tr>
<tr>
<td>Grandchildren</td>
<td>10 (67%)</td>
<td>13 (87%)</td>
<td>.024</td>
</tr>
<tr>
<td>NYHA</td>
<td></td>
<td></td>
<td>.392</td>
</tr>
<tr>
<td>- NYHAIi</td>
<td>11 (73%)</td>
<td>9 (60%)</td>
<td></td>
</tr>
<tr>
<td>- NYHA III</td>
<td>4 (27%)</td>
<td>5 (33%)</td>
<td></td>
</tr>
</tbody>
</table>
Increasing exercise capacity and quality of life of patients with heart failure through Wii gaming: the rationale, design and methodology of the HF-Wii study; a multicentre randomized controlled trial

Tiny Jaarsma¹*, Leonie Klompstra¹, Tuvia Ben Gal², Josiane Boyne³, Ercole Vellone⁴, Maria Bäck⁵, Kenneth Dickstein⁶, Bengt Fridlund⁷, Arno Hoes⁸, Massimo F. Piepoli⁹, Oronzo Chialà⁴, Jan Mårtensson⁷, and Anna Strömberg¹⁰
Objectives HF-Wii study

To determine the effectiveness of structured access to a Wii game computer compared to ‘motivational support only’ in heart failure on

1. Exercise capacity and daily activity.
2. Mortality, readmission and quality of life

www.HF-Wii.com
Randomized controlled Trial (HF-WII)

- Theme 1: Patient outcomes related to exercise and activity
- Theme 2: Patient outcomes related to self-care, readmission, survival and quality of life
- Theme 3: Costs
- Theme 4: Patient experiences

Case study and pilot study
In total 369 patients included!

62% Included in the study
Increase in the proportion of publications with more than one international author, 1996–2008

Knowledge, Networks and Nations: Global scientific collaboration in the 21st century, RS Policy document 03/11
Citations per article versus number of collaborating countries

Knowledge, Networks and Nations: Global scientific collaboration in the 21st century, RS Policy document 03/11
My publication profile
During the first two years of Horizon 2020 (Work Programme for 2014/15), the EU will invest some €1.2 billion in this Challenge.

**Personalising health and care**

Research & Innovation supported by this call will:

- improve our understanding of the causes and mechanisms underlying health, healthy ageing and disease;
- improve our ability to monitor health and to prevent, detect, treat and manage disease;
- support older persons to remain active and healthy;
- and test and demonstrate new models and tools for health and care delivery.
US hubs
Asian hubs
Success in international collaborations

- Attend as many international events as possible
- Seek mentorship
- Stay focused on your goals and the important questions
- Plan carefully, but be open for unexpected opportunities
- Approach the frontline researchers and team up with them
- Build and keep international collaborations
- Apply for funding that supports international collaboration
  - EU funding
  - Fulbright
  - Le Duc
  - ....
Success in international collaborations

• Never think first what’s in it for me, but what can be achieved and how can I contribute
• Always support others and you will have a lot of support!
• Be ready to leave a collaboration that is not working
The Road Not Taken

(Robert Frost 1874-1963)

Two roads diverged in a wood, and
I took the one less traveled by,
and that has made all the difference
International collaboration

Leads to missions & approaches otherwise not possible