Building Successful International Research Collaborations

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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
Versions

The EHFSCE 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 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>מספרпись</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. anunci שקדא את עצמי כל יום</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. anunci יש לי קוצר נשימה איני נוח</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. anunci קוצר נשימה שלתי מתרבה איני מתכשתרת/ת</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. anunci גללי נPKGות יותר מרגליי איני מתכשתר/ת</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Self-Care around the world

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 Pulignano\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}

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\textsuperscript{o}Cardiology Unit, Aracaju Hospital, Aracaju, Brazil
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\textsuperscript{s}Department of Social and Welfare Studies, Linköping University, Linköping, Sweden
\textsuperscript{t}Department of Cardiology, Charité University Hospital, Berlin, Germany
Self-care around the world: % low self care in exercise in Heart Failure patients
Nordforsk project 2015-2018

Symptom monitoring after hospitalisation in patients with advanced heart failure – A Nordic-Baltic study

Memorial Symptom Assessment Scale-Heart Failure (MSAS-HF)

Vennligst sett ring rundt Nei eller Ja i Kolonne 1 for å fortelle oss om du har noen av følgende symptomer i dag. Om du setter ring rundt i for et symptom, så sett ring rundt riktig tall i kolonne 2 (hvor ofte), 3 (hvor ille), og 4 (hvor plagsamt) som angir din opplevelse av symptomet. Om du setter ring rundt Nei i kolonne 2, så svar Nei på spørsmålene i kolonne 2, 3, og 4 for det symptomet, og gå videre til neste symptom.

<table>
<thead>
<tr>
<th>Symptomer</th>
<th>Kolonne 1</th>
<th>Kolonne 2</th>
<th>Kolonne 3</th>
<th>Kolonne 4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Har du?</td>
<td>Hvor ofte har du det?</td>
<td>Hvor ille er det?</td>
<td>Hvor sterkt plages du av det?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Har ikke hele tiden</td>
<td>Svakt</td>
<td>Ekstremt</td>
</tr>
</tbody>
</table>

Pust
1. Kortpustethet    
   Nei Ja 1 2 3 4 5 1 2 3 4 5
2. Pustebesvær når legger flat? 
   Nei Ja 1 2 3 4 5 1 2 3 4 5
3. Kortpustethet under arbeid 
   Nei Ja 1 2 3 4 5 1 2 3 4 5
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 → Improved mediating factors → Improved outcomes

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

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

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.
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>Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>63 (±14)</td>
<td></td>
</tr>
<tr>
<td>Female Sex</td>
<td>10 (32%)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Above high school</td>
<td>18 (57%)</td>
<td></td>
</tr>
<tr>
<td>Marital state</td>
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</tr>
<tr>
<td>- Married/relationship</td>
<td>26 (84%)</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>28 (90%)</td>
<td></td>
</tr>
<tr>
<td>Grandchildren</td>
<td>23 (74%)</td>
<td></td>
</tr>
<tr>
<td>New York Heart Association class (NYHA)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- NYHA II</td>
<td>21 (68%)</td>
<td></td>
</tr>
<tr>
<td>- NYHA III</td>
<td>9 (29%)</td>
<td></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>
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<tbody>
<tr>
<td></td>
<td>N=15</td>
<td>N=15</td>
<td></td>
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<tr>
<td>Children</td>
<td></td>
<td></td>
<td>.334</td>
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<tr>
<td></td>
<td>14 (93%)</td>
<td>14 (93%)</td>
<td></td>
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<tr>
<td>Grandchildren</td>
<td></td>
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<td>.024</td>
</tr>
<tr>
<td></td>
<td>10 (67%)</td>
<td>13 (87%)</td>
<td></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
HF-Wii

Baseline assessment → R → Structured access to a Wii game computer (Wii) → 3 month follow-up → 6 month follow-up → 12 month follow-up

Motivational support only (Control) → 3 month follow-up → 6 month follow-up → 12 month follow-up

Greetings from Israel

Autumn 2015
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
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

Self-Care Management

Response to changes in physical and emotional signs/symptoms

Entails treatment implementation and the evaluation of treatment

 Treatments are often specific to the signs and symptoms of a particular chronic illness:

- Asthma: use a bronchodilator for shortness of breath
- Diabetes: eat for low blood glucose
- Heart failure: take an extra diuretic for shortness of breath

Self-care management requires attention to the effectiveness of a treatment to evaluate whether or not that approach should be tried again in the future.
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