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## **Patients' and relatives' experiences of transitions**

Uhrenfeldt, Lisbeth

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# PATIENTS' AND RELATIVES' EXPERIENCES OF TRANSITIONS

Systematic reviews and metasynthesis based on Sandelowski and JBI approaches

Lisbeth Uhrenfeldt,Phd,RN, ass. Prof. / PRANSIT members\*



# WHY EXPLORING EXPERIENCES?

The German philosopher Hans–Georg Gadamer (1900-2002) ”made important philosophical clarification in the area judgment and discernment and how these matters relate with conscience” (Uhrenfeldt 2007: 39)

In seeking truth, there are four guiding concepts: bildung (knowledge), sensus communis (moral experience & knowledge), judgment (situated knowledge) and taste (critical distinctions & choices). (Uhrenfeldt 2007).

Experiences as a situated ‘truth’ uses language in sharing with others the meaning of these. (Uhrenfeldt 2007). This ‘truth’ may be developed in hermeneutic movements aiming for ‘fusions of horizon’.



Truth &  
Method

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# WHY PATIENTS AND RELATIVES?

There seems to be an global understanding in the western world that patients request to be taken serious (Fegran et al. 2014).

Professionals are talking about: Patient-centered care (Stewart 2001), patient involvement (Faber et al 2014), patients' self-management (Cramm et al. 2013), a.s.o.

From child care and obstetric nursing, we are used to 'family-centered' approaches (Shields et a. 2012), it seems that the relatives/significant others/ next of kin are being included in the care planning in a new way in other age groups too. (Uhrenfeldt et al. 2014).



# Why secondary research?



Systematic  
reviews &  
meta-  
synthesis

*“.. secondary analysis holds considerable promise for optimizing the health knowledge that can be constructed ...methodological developments to guide design and evaluation of this research have not been fully explored ..two specific concerns arising from secondary analysis: ethics and representation.”* (Thorne 1998, p 547).

# Why secondary research?



Systematic  
reviews &  
meta-  
synthesis

*“Time pressures are inherent in the policy-making process and in many circumstances it is not possible to seek funding, conduct and analyse new qualitative studies of patients' experiences in time to inform a specific policy. The danger then is that the patient voice, and the experiences of relatives and carers, is either excluded or included in a way that is easily dismissed as ‘unrepresentative’. We argue that secondary analysis of qualitative data collections may sometimes be an effective means to enable patient experiences to inform policy decision-making.”* (Ziebland & Hunt 2014)

# What is secondary research?

Qualitative metasynthesis ‘refers to both an interpretive product and the analytic processes, by which the findings of studies are aggregated, integrated, summarized, or otherwise put together’ (Barroso et al. 2003, p. 154).

This meta-synthesis was a product of the reviewers’ construction of the primary researchers’ interpretation of the data generated from what the research participants disclosed about their experiences. (Uhrenfeldt et al. 2013).

The themes or concepts presented finally in a meta-synthesis are far removed from the original experiences-as-lived or experiences-as-told disclosed to the primary researchers; they are ‘the re-interpretation and integrated interpretations’ (Sandelowski & Barroso 2007, p. 236, Uhrenfeldt et al. 2013).



# Secondary research: A systematic approach

- Standardization of research questions
- Peer-reviewed protocol & publication  
(JBI Library)
- Critical appraisal
- Aggregation
- Using JBI templates  
and instruments

**Joanna Briggs Institute as collaborative partner  
PICO, PICO, PIRO Reviewers Manual, Work Books...**





# Why transitions?



Transitions

Afaf Meleis, presenting, e.g.

2011: Transition- the theory (0-1.04)

<https://www.youtube.com/watch?v=xSn2qqmcwaA>

2014: Urban situation for girls and  
women- global health (0-2)

<https://www.youtube.com/watch?v=U-3B67giQSo>

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# \*PRANSIT

## **Acknowledgement**

My recent experiences working with qualitative metasyntheses and systematic reviews in the time period 2009-2014 are based on the collaboration in the Scandinavian-German research network:

**P**atient and **r**elatives' transfer and **t**ransition in hospitals (PRANSIT).

(Focus: patients of all ages). The network members are:

- *Associate professor Liv Fegran, phd, Agder University, Kristiansand, Norway*
- *Professor Gabriele Meyer, phd, Martin-Luther University, Halle, Germany (Studies concerning adults.)*
- *Professor emeritus EOC Hall, phd, Aarhus University, Denmark*
- *Senior researcher Mette Spliid Ludvigsen, phd, Randers Regional Hospital, Denmark*
- *Senior researcher Hanne Aagaard, phd, Aarhus University Hospital, Denmark*
- *Associate professor Lisbeth Uhrenfeldt, phd, Aalborg University, Denmark.*

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# 1: How do adolescents and young adults (YA) with chronic diseases experience transition from paediatric to adult hospital care?



This research question became relevant for our research team, due to recent discussions in DK and Norway about the possibility of establishing specific wards for youngsters; but a clear understanding lacked, of:

- what should qualify the establishment of such hospitals ward and
- what age limits should be adequate for such a ward

# Adolescents and young adults



Adolescents  
& Young adults


Transition from to adult care constitutes an important health care issue (Fegran et al 2014)

- In western countries around 10% of the adolescents suffer from chronic conditions (Michaud et al 2007/Fegran et al 2014)
- Staff on adult wards are not always prepared to receive the young patients and facilitate the transitions experienced in child-centred care to adult-centred care (ibid)

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# Qualitative metasynthesis (Sandelowski & Barroso 2007)



Adolescents  
& Young adults

This is a scientific inquiry with a specific fokus aimed at systematically interpreting and integrating findings in reports of qualitative research (Fegran et al 2014)

Five steps:

1. Formulating the purpose and rationale
2. Searching for and retriving qualitative research about adolescents or YA´experiences of transfer from paediatric to adult wards
3. CA using JBI checklist (JBI 2008).Final inclusion (n= 18): Is the patients voice adequately represented? (Fegran et al 2014)
4. Classifying the findings
5. Synthesizing the findings

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# Qualitative metasynthesis (Sandelowski & Barroso 2007)

## Classifying the findings (Fegran et al 2014)

- Metasummary, quantitative oriented aggregations (Effect size)
- Metasynthesis, based on Ricoeur inspiration:
  - 1) Naive reading of extracted text,
  - 2) Interpretation into categories and themes,
  - 3) Themes and summaries were aggregated and critically interpreted

## Synthesizing the findings

- Main theme: **Being in a limbo moving from a familiar to unknown ward cultures and achieving responsibility, depending on timing of transfer and facing changes in significant relationships**
- Sub-themes: **Facing changes in significant relationships; Moving from familiar to unknown ward cultures; being prepared for transfer; Achieving responsibility**



Adolescents  
& Young adults

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## Strengths and limitations

The number of participants (n=368) gave sufficient in-dept knowledge


Experiences across diagnosis, all somatic chronic conditions were included

- "Conducting a metasynthesis as a research team contributed to the methodological development, we found it stimulating in searching additional literature and analyzing findings". (Fegran et al 2014)



Adolescents  
& Young adults

# Conclusion



Adolescents  
& Young adults

Feelings of not belonging and of being redundant are striking.

Despite years of research concerning transfer and transitions among adolescents and young adults, there is a need to use this synthesis to improve nursing practice!

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## 2: How do patients experience being transferred/in transition from one hospital to another or from ward to another?

This research question became relevant for our research team due to the fact that the present economic situation in Europe still increases the amount of transfers among patients.

This provided a contextual relevance for us to initiate this study.

We wanted to forward the patients experiences regarding transfer; and their insight as far as what transitions this brought to them and

- to end up by suggesting nursing therapeutics relevant for clinical nursing

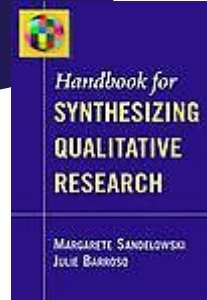


## Design

We used Sandelowski and Barrosos Handbook (2007)

- as this is based on a thoroughly stepwise approach from primary studies, through a solid literature search, structured as well as unstructured, and
- founded an aggregated summary, effect measure and synthesis, and
- Finally, made it possible to move on to advice on nursing practice (Uhrenfeldt et al 2013)


Intra-and inter hospital transfer



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# Qualitative metasummary



Qualitative  
metasummary  
Study 2

- Our literature search, resulted in 194 papers, PRISMA statement was used

(PRISMA stands for Preferred Reporting Items for Systematic Reviews and Meta-Analyses).

- Screening with a critical appraisal tool (JBI 2008) and inclusion criteria reduced the amount to 11 papers.
- An additional 11 studies were found through citation and reference lists of which 3 was included.
- In total, 14 studies representing 288 patients originated from individual or focus group interviews, were included in the present metasynthesis.

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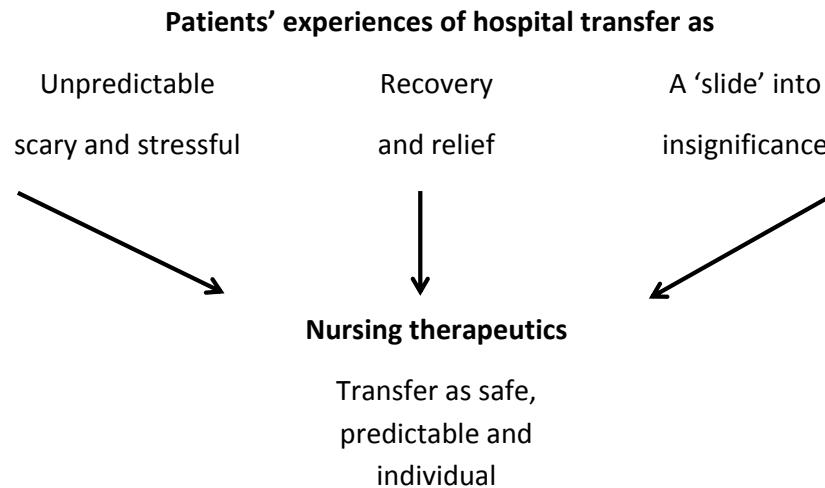
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## Studie 2 (Uhrenfeldt et al. 2013, p1682)

Based on 14 studies (1999-2011) from three continents, we found evidence that patients who experienced transfers between hospitals, wards, out-patient departments a.s.o. found it very troublesome (Uhrenfeldt et al 2013):



Figure 2. Conceptual mapping of findings and nursing therapeutics



# Conclusions

Implications for staff:

”The risk of sliding into insignificance was opposed by the quality of interaction among healthcare staff and patients, built on certain milestones unhurried atmosphere, normality, security, control, and being a good experience”. (Uhrenfeldt et al. 2013,

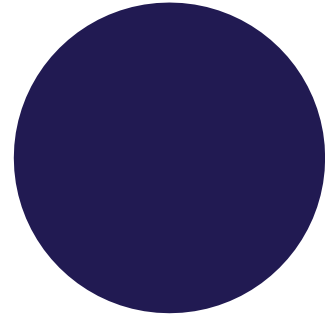
p.1687)

”In a time where healthcare staff implemented self-management strategies and other adaptation plans for timely discharge, there was a risk of patients being left alone if they showed signs of early recovery” (ibid.)



Intra- and inter  
hospital transfer  
Study 2  
(Uhrenfeldt et al. 2013)

## Strengths and limitations (Uhrenfeldt et al. 2013, p1688)



Strengths are:

It covered a time range of 13 years and the views of patients from a wide cultural group (e.g. gender and setting) of health care.

The frequency of occurrence of primary studies in the three categories validated the construction of the actual categories as strengths.

A limitation may be that this metasynthesis did not add specific knowledge about how poorly coordinated care led to an increase in readmissions.

## And....

The most recent study identified (Forsberg et al. 2011) did not contribute much to the existing body of knowledge from 10 years of research. Therefore, this metasynthesis also brings to our attention the need to stop descriptive studies in this field as patients' experiences are now extended beyond single events or single responses into implications for health staff.

There exists sufficient knowledge to move forward to policy making, clinical leadership and interventions (practice and research).



However....

# Last year, I recruited Center for clinical guidelines - a collaborative center with The Joanna Briggs Institute

Moving forward....

From 2008-2014, I was clinical research lead in nursing at Horsens Hospital in Denmark.

Many of our CNS were curious about how to develop clinical topics into research questions and later a PhD study.

I argued for systematic reviews as a solid gateway,



Fotos 1-2: Horsens Regional Hospital

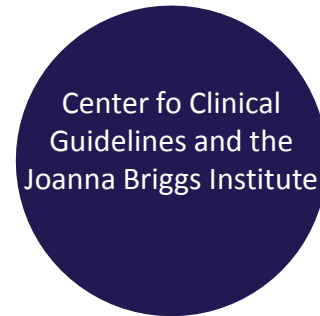


## During september 2013-january 2014

We presented clinical relevant topics, formulated PICO/PICo's, learned about relevant instruments and support systems and submitted protocols by the end of the seminar.

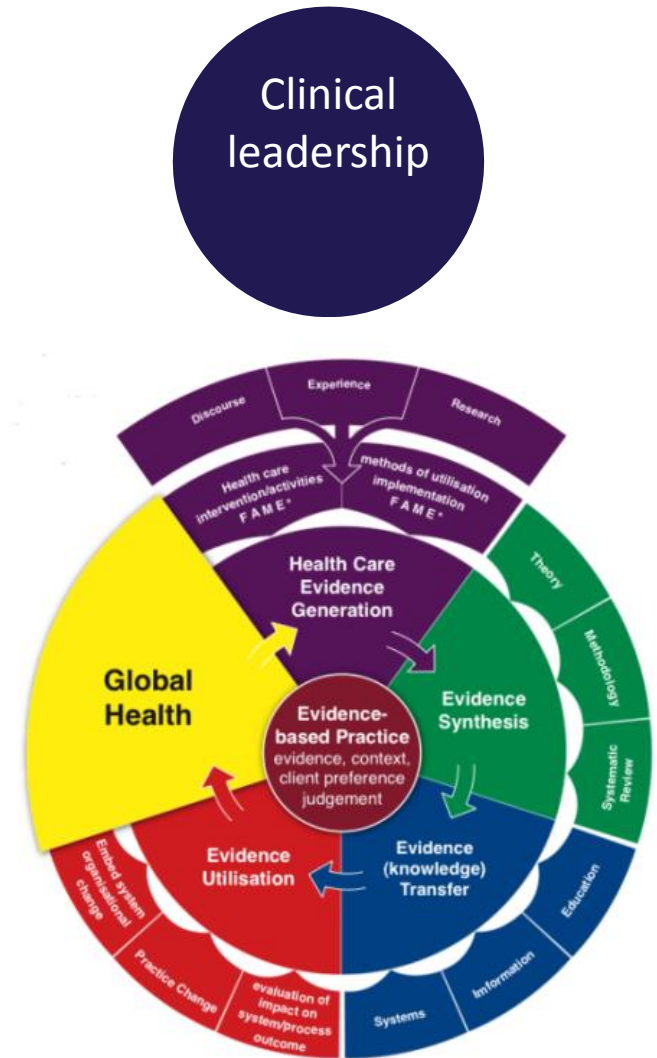
The main outcome for these 10 clinical specialists (7 nurses + 3 physiotherapists) was:

- their own stringent and transparent movement from an immediate wonder in a clinical context
- into addressing this wonder by a qualified specific
- research question and
- receiving peer-review on the protocol.
- Finally publishing their protocols.



# So why is this experience from Horsens interesting for us today?

Because, this process also needs support from clinical leadership, and the JBI model for evidence-based practice is showing us the way:



# E.G: THIRD EU HEALTH PROGRAMME 2014-2020

- GLOBAL HEALTH:

- [HTTP://EC.EUROPA.EU/HEALTH/PROGRAMME/DOCS/EV\\_20141104\\_CO01\\_EN.PDF](http://ec.europa.eu/health/programme/docs/ev_20141104_co01_en.pdf)

**The scope of the Programme**

European Commission

Promoting health

Encouraging innovation in health

Protecting citizens from serious cross-border health threats

Increasing the sustainability of health systems

Complement, support and add value to the policies of MS to improve the health of EU citizens and reduce health inequalities

Health and Consumers

**THE CHALLENGES**

European Commission

→ Regulation 282/2014/EU for the third Health Programme (OJ L 86, Vol. 57 of 21 March 2014)

[http://ec.europa.eu/health/programme/policy/index\\_en.htm](http://ec.europa.eu/health/programme/policy/index_en.htm)

increasingly challenging demographic context threatening the sustainability of health systems

fragile economic recovery limiting the resources available for investment in healthcare

increase of health inequalities between/within Member States

increase in chronic diseases prevalence

pandemics and emerging cross-border health threats

rapid development of health technologies

- Following the Commission's proposal of November 2011

- 7 years, proposed budget of € 449.39 million

- Other Programmes for health are:

- Horizon 2020,
- Structural and Investment funds

Health and Consumers

**The future Programme: a tool for investing in health(\*)**

European Commission

for spending smarter but not necessarily more in sustainable health systems

for investing in people's health, particularly through health-promotion programmes

for investing in health coverage as a way of reducing inequalities and tackling social exclusion

(\*) Investing in health – Commission staff working document – published in February 2013 as part of the Social Investment Package for growth and cohesion.

Health and Consumers



European Commission

## Global health

# The objectives

1) Promote health, prevent disease and foster supportive environments for healthy lifestyles

2) Protect citizens from serious cross-border health threats

3) Contribute to innovative, efficient and sustainable health systems

4) Facilitate access to better and safer healthcare for Union citizens



Policy - European Comm... ec.europa.eu/health/pro... ec.europa.eu/health/pro... ec.europa.eu/health/programme/docs/ev\_20141104\_co01\_en.pdf



### 1) Promoting health, preventing diseases and fostering supportive environments for healthy lifestyles

- Cost-effective promotion and prevention measures for addressing **tobacco, alcohol, unhealthy dietary habits, physical inactivity**
- action in **reducing drug-related health damage, including information and prevention.**
- **Chronic diseases** including **cancer**; good practices for prevention, early detection and management, including self-management
- **HIV/AIDS, TB and hepatitis; up-take of good practices for cost-effective prevention, diagnosis, treatment and care**
- **Legislation on tobacco products** advertisement and marketing
- **Health information** and knowledge system

# Understanding the movement from global health via research and knowledge transfer into patients' experiences

Clinical leadership



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THANK YOU\*

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