

# 6<sup>th</sup> OCHER workshop on Clinical Communication Research

January 11-13, 2017

The Oslo Communication in Healthcare Education and Research (OCHER) group

The aims of OCHER workshops are two:

- 1) To provide a fruitful arena for discussion of research projects at all stages of development, with particular attention to challenges in methodology
- 2) To build a Scandinavian network (with international collaboration partners) of multidisciplinary researchers with interest in communication in health care

### Program

| Start:<br>End: | Wednesday 11 January, 10:00<br>Friday 13 January, 16:00 |  |  |
|----------------|---|--|--|
| Venue:         | Thon Hotel T<br>Address:                                | F <b>riaden</b> , Lørenskog, Norway<br>Gamleveien 88<br>1476 Rasta |  |
|                | Telephone:  | +47 66 10 97 00  |  |

### Lecturers and group discussants:

# **Professor J. Randall Curtis**, University of Washington, Seattle, USA *Keynote titles:*

- Measuring and improving communication about palliative care: What have we learned and where do we go from here?
- Communication and decision-making with families of critically ill patients: Lessons from the successes and failures

# **Professor Vikki Entwistle**, University of Aberdeen, Scotland, UK *Keynote titles:*

- \_\_\_\_\_Support for self-manager
  - Support for self-management among people with long-term conditions: re-formulating the concept to reflect and promote good practice
  - "How will we know if I've done a good job?" The challenges of evaluating personcentred care

Local faculty: Pål Gulbrandsen, Arnstein Finset, and Jan Svennevig, University of Oslo, Hilde Eide, University College of Southeast Norway, Jennifer Gerwing, Akershus University Hospital

Working languages: English, Scandinavian

|       | Wednesday January 11        |  |                                    |  |
|-------|-----------------------------|--|------------------------------------|--|
| Time  | Activity                    | Plenary room / Room A  | Room B                             |  |
| 1000  | Plenary                     | Introduction, mutual presentation                                    |                                    |  |
| 1045  | Break                       |  |                                    |  |
| 1100  | Plenary                     | Vikki Entwistle  | Support for self-management        |  |
| 1100  | keynote 1                   |  | among people with long-term        |  |
|       | 5                           |  | conditions: re-formulating the     |  |
|       |                             |  | concept to reflect and promote     |  |
|       |                             |  | good practice                      |  |
| 1230  | Lunch                       |  |                                    |  |
| 1315  | Plenary                     | J. Randall Curtis  | Communication and decision-        |  |
|       | keynote 2                   |  | making with families of critically |  |
|       |                             |  | ill patients: Lessons from the     |  |
|       |                             |  | successes and failures             |  |
| 1415  | Break                       |  |                                    |  |
| 1430  | Groups                      | Session A1   | Session B1                         |  |
|       |                             | Roles, interactions, and discourse                                   | Narratives as patient aids         |  |
|       |                             | Johansen   | Brembo                             |  |
| 1.500 | <b>D</b> 1                  | Wallander Karlsen  | Birkemose                          |  |
| 1530  | Break                       | <i>a</i>   |                                    |  |
| 1545  | Groups                      | Session A2   | Session B2                         |  |
|       |                             | Personal awareness   | Virtual reality and tele-          |  |
|       |                             | E stur su u  | communication                      |  |
|       |                             | Fogtmann   | Amundsen                           |  |
| 1645  | End Cround                  | Ørnes  | Steinsbekk                         |  |
| 1045  | End Groups<br>Walk to Pål's |  |                                    |  |
| 1/13  | house for get-              | The walk is 20 minutes Shoos should stand snow Follow asth on more   |                                    |  |
|       | together                    | The walk is 20 minutes. Shoes should stand snow. Follow path on map! |                                    |  |
| 2000  | Dinner at                   |  |                                    |  |
| 2000  | hotel                       |  |                                    |  |
|       | noter                       | Thursday January 12  |                                    |  |
|       | ~                           |  |                                    |  |
| 0830  | Groups                      | Session A3   | Session B3                         |  |
|       |                             | Framework development  | Health literacy and information    |  |
|       |                             |  | needs                              |  |
|       |                             | Ilstad   | Von Possel                         |  |
| 0020  | Dural                       | Callon   | Lie                                |  |
| 0930  | Break                       | Session A4   | Session B4                         |  |
| 0945  | Groups                      | Session A4<br>New methods  |                                    |  |
|       |                             | Van Dulmen   | Conversation analysis<br>Svennevig |  |
|       |                             | Sundling   | Van der Laaken                     |  |
| 1045  | Break                       | Sunding  |                                    |  |
| 11045 | Plenary                     | J. Randall Curtis  | Measuring and improving            |  |
| 1100  | keynote 3                   | J. Kanuan Cut us   | communication about palliative     |  |
|       | Keynole 5                   |  | care: What have we learned and     |  |
|       |                             |  | where do we go from here?          |  |
|       | 1                           |  |                                    |  |

| 1245 | Groups               | Session A5                    | Session B5                        |  |  |
|------|----------------------|-------------------------------|-----------------------------------|--|--|
|      |                      | Forming collaborative groups  | Forming collaborative groups      |  |  |
| 1430 | Break                |                               |                                   |  |  |
| 1500 | Groups               | Session A6                    | Session B6                        |  |  |
|      |                      | Coding and measuring emotions | Cross-cultural challenges         |  |  |
|      |                      | Eide                          | Berbyuk-Lindström                 |  |  |
|      |                      | Tranberg                      | Leonhardt                         |  |  |
| 1600 | Plenary              | Vikki Entwistle               | "How will we know if I've done a  |  |  |
|      | keynote 4            |                               | good job?" The challenges of      |  |  |
|      |                      |                               | evaluating person-centred care    |  |  |
| 1630 | Break                |                               |                                   |  |  |
| 1645 | Groups               | Session A7                    | Session B7                        |  |  |
|      | 1 I                  | Unpleasant information        | Shared decision-making            |  |  |
|      |                      | Løkkeberg 1                   | Hultberg                          |  |  |
|      |                      | Løkkeberg 2                   | Ammentorp                         |  |  |
| 1745 | End Groups           |                               | •                                 |  |  |
| 1900 | Dinner at            |                               |                                   |  |  |
|      | hotel                | company                       |                                   |  |  |
|      |                      | Friday January                | 13                                |  |  |
| 0830 | Groups               | Session A8                    | Session B8                        |  |  |
| 0050 | Groups               | Interventions                 | Nurses' responses to emotions     |  |  |
|      |                      | Nordfalk                      | Hafskjold                         |  |  |
|      |                      | Mellblom                      | Höglander                         |  |  |
| 0930 | Break/               |                               |                                   |  |  |
| 0750 | Check-out            |                               |                                   |  |  |
| 1000 | Plenary              | Jette Ammentorp               | Healing health communication –    |  |  |
| 1000 | workshop             | ·····                         | moving relationships              |  |  |
| 1115 | Break                |                               |                                   |  |  |
| 1130 | Groups               | Session A9                    | Session B9                        |  |  |
|      | 1                    | Experimental approaches       | Patient stigma, patient resources |  |  |
|      |                      | Holt                          | Beach                             |  |  |
|      |                      | Haaland                       | Krístjansdottir                   |  |  |
| 1230 | Lunch                |                               |                                   |  |  |
| 1315 | Dianamy              | Innifor Comming               | Project-oriented sequence         |  |  |
| 1515 | Plenary<br>keynote 5 | Jennifer Gerwing              | analysis: A proposed meta-method  |  |  |
|      | Keynote 5            |                               | for analyzing clinical practice   |  |  |
| 1400 | Break                |                               |                                   |  |  |
| 1400 | Groups               | Session A10                   | Session B10                       |  |  |
| 1415 | Groups               | Work in collaborative groups  | Work in collaborative groups      |  |  |
| 1500 | Plenary              | Evaluation and round-up       | work in conaborative groups       |  |  |
| 1500 |                      |                               |                                   |  |  |
| 1530 | End                  |                               |                                   |  |  |

### Session A1 – Roles, interactions, and discourse

# Social workers' discourse about children who experience domestic violence

### Ann-Kristin Johansen

This article presents an analysis of social workers' discourse about children who experience domestic violence. The data consist of interviews with 12 employees within family counseling and child welfare services in four different regions of Norway. The question asked is: How are dominant discourses reflected in informants' descriptions of children who experience domestic violence and what are the consequences for social workers' practice? The analysis shows that the informants encounter a variety of ethical and practical dilemmas in cases where children experience domestic violence. Significant differences were found between how social workers discursively expressed their ideals and how they acted in practice. When helpers spoke generally about children and violence they employed the discourse of the competent child and defined violence more broadly. However, when helpers moved from a position of looking in from the outside to that of experiencing a situation, they employed a discourse of physical and specific violence, and the traditional discourse about children as vulnerable was dominant. We discuss the available positions, possible dilemmas, paradoxes and challenges highlighted by social workers' discursive practice.

# Communication and interaction with conscious and alert critically ill patients during mechanical ventilation: Being a researcher in your own field

Marte Marie Wallander Karlsen and Lena Heyn

### Aims

The aim of the study is to obtain more in depth knowledge about interactions between healthcare personnel and patients who are conscious and alert on mechanical ventilation in Intensive Care Units (ICUs). It is a PhD-project and collaboration between Lovisenberg Diaconal University College, University of Oslo and Oslo University Hospital.

### Methods

This is a qualitative study with a hermeneutic-phenomenological approach. 10 video recordings of natural occurring interaction in different contexts between health personnel and patients on mechanical ventilation constitute the data for this study. The videos are between 2-4 hours in duration. In addition, interviews were conducted afterwards, both with healthcare personnel and with patients.

One challenge when collecting data for this study was the fact that the researcher works at the same ICU as data were collected. Thus, a continuous reflection about role and the possible consequences for the data collected arose. The recruitment of patients was done with a sensitive approach, both towards the patients and healthcare personnel. Implications of not being reflective and aware of the potential pitfalls, pose a threat for both the credibility of the findings and the analytic process in general. So the choices made methodologically in preparation of the study and during the fieldwork have highly influenced the data collection period. Main issues that will be addressed in the presentation are 1) which type of distance or proximity one may adapt towards the participants 2) how to put on a research hat in a familiar clinical field and 3) ethical considerations when recruiting patients in critically illness without possibilities to consent verbally. This will be exemplified with narratives of concrete situations. The way it has been done could be useful to discuss and get feedback on.

### **Session B1 – Narratives as patient aids**

# Informing didactics of patient decision aids for persons with osteoarthritis by knowledge on barriers according to Theory of Planned Behaviour (TPB)

### Brembo E., Lauritzen M., Lager A. R., Rumpsfeld M., van Dulmen, S., Eide H. & Kasper J.

**Background:** Decision aids developed using the DAfactory approach are offered to patients and health professionals via the web-based platform '*Mine Behandlingsvalg*', which in time will become an integrated part of the national health platform '*helsenorge.no*'. A component in the DA factory approach is developed to motivate users of the decision aids by subjecting potential barriers towards patient involvement. The method includes careful assessment of specific barriers of the patient group and video-based provision of patient stories telling about such barriers. At the best of our knowledge, such narratives have not been used or evaluated as components of decision aids in the way like in DAfactory. Complex interventions require stepwise evaluation and increasing evidence, including evaluation of single components. Patients with osteoarthritis (OA) make decisions when they are referred to an orthopedic outpatient evaluation. During consultations, the patient and surgeon need to make careful considerations about the risks and benefits of both surgical and non-surgical treatment alternatives.

**Objective**: The study involves preliminary evaluation of a newly developed video-based component of a patient decision aid aiming to facilitate SDM. The study should increase knowledge about how reception of patient narratives on barriers towards SDM is processed by patients with osteoarthritis considering joint replacement. The study aim implies investigation of the patients' internal reactions with focus on the potential to reduce motivational barriers to actively involve themselves in making their medical decisions.

**Methods**: The study comprises three methodological steps using qualitative methods: 1. Assessment of TPB related barriers within the context of hip or knee OA, following the method described by Kasper et al. (in manuscript). 2. Development of a video based on the didactic approach and production of patient narratives. 3. Investigation of internal processing to better understand how these narratives facilitate the patients' engagement in SDM. Focus on the OCHER workshop: This is work in progress. We would like any relevant feedback concerning methodological or theoretical aspects.

# Video-informed shared decision-making, end-of-life: How to investigate the effects?

### Christina Birkemose

### END OF LIFE CONVERSATIONS

How do terminal patients and their relatives talk about dying? How can healthcare providers work systematically with the need of patients and relatives *in having conversations about End of Life* from an everyday lifeworld perspective?

Helbredsprofilen.dk displays patients' perspectives on among other things "End of Life" and "Palliative Care".

The videos on <u>www.helbredsprofilen.dk</u> are recorded in cooperation with Patients, their Relatives and Professionals within the field of Palliative Care. In the videos, Patients and Relatives share their thoughts and emotions considering what was important to them, when they first learned that there were no curing treatment for the disease, e.g. cancer. Here, patients also describe, in their own words (they do not get manuscripts), their thoughts and beliefs when it comes to the aftermath, religious questions and what they pay forward to their relatives.

Video-recordings of patients in palliative care and conversations about End of Life, might or might not be an effective way of communicating sensible issues to new patients and their families. Similarly, the possibility of watching and listening to the material on video provides space for patients to get the information repeated.

*Can video-information qualify Shared Decision Making with critically ill patients and their families – and how can we measure the effects?* 

LINK: https://helbredsprofilen.dk/artikel/jeg-lever-i-nuet?category=858

### Session A2 – Personal awareness

# Analysing implicit mentalization in physicians' consultations

### Christina Fogtmann, Annette Sofie Davidsen, University of Copenhagen

The concept of mentalization designates a general human capacity and is described as being aware of one's own mental states and those of others. It is considered to be an important skill in relation to therapists' capacity to understand patients. Mentalization can be both explicit and implicit. Explicit mentalization is a conscious, often verbal and controlled process. Implicit mentalizing is automatic, non-verbal, immediate, and unreflective. Implicit mentalization is seen as the most important component in all forms of professional understanding.

However, there are no descriptions of how implicit mentalization is enacted or how it can be identified when displayed online in clinical interaction. We aim to put forward and implement a method for studying online implicit mentalization, and we suggest that this can be done by employing Conversation Analysis (CA). CA has identified the orders and rules that interactants rely on and apply in order to establish shared understanding, and CA has identified a sequential approach that can be applied to study interactants' sensitivity to co-interactants' mental states. We suggest that this sequential approach and the knowledge attained by CA can convey a systematic account of online implicit mentalization. We use data from a study of GPs' consultations with patients with depression to illustrate different ways of how implicit mentalization is displayed by physicians and how this can be shown in a CA analysis.

# "I don't know how to be professionally empathic": defending conclusions from my Ph.D. work

### Knut Ørnes (1,2), Arnstein Finset (2), Reidar Pedersen (1)

(1) Centre for Medical Ethics, (2) Department of Behavioural Sciences in Medicine, (2); both at the University of Oslo e-mail: knut.ornes@medisin.uio.no

In this presentation/discussion, I would like to defend one of the main conclusions of my Ph.D. work; that there is no or little room for students' individual emotional reactions when conducting a medical interview with a patient. This conclusion is based on the results from the analysis of medical interviews conducted by 11 3<sup>rd</sup> year medical students on simulated patients as well as stimulated recall interviews of students using three different methodological approaches:

- A qualitative content analysis of student utterances initiating and responding to emotional talk revealed that students either approached patient emotion as a relevant object for interviewing by ensuring that their own interpretation corresponds to that of the patient's, as non-relevant to the medical interview by partially or completely ignoring patient emotion with further medical questioning, or as a clinically relevant or potentially pathological object which can be quantified and acted on by means of professional knowledge.
- 2. Conversation analysis further demonstrated how underlying sequential pattern of the interviews which permitted the exclusion of the student's own emotional stance: by the student first taking the role of a story-teller recipient, interviews on the specifics on the patient's trouble story, at story-completion returns to biomedical questioning using formulations of the patient's emotional stance as closing-devices and then potentially provides a reappraisal of the patient's emotional stance where institutional interpretations of the patient's stance such as information or positive reappraisals are made relevant.
- 3. Qualitative content analyses of stimulated recall interviews revealed that the task of obtaining a complete medical history was considered more important than the patient's emotional utterances. Although many students mentioned identifying with the patient, they found it difficult to remember their own emotional reactions in the interviews, but expressed having had altruistic emotions for the patient when they did. Students presented interpretations of the patient's emotional utterances in terms of their new professional roles; they evaluated the validity in the patient's claims, highlighted the patient's need to share emotions, or found clinical relevance in emotions which they could act on as professionals. All students mentioned using strategies or skills learnt during their studies for dealing with patients' emotions. While some students felt that these strategies limited their possibilities to be empathic, other students reported that they behaved more empathically than they what they deemed appropriate for a professional.

# Exploring tele oncology in North Norway – an RCT focusing on quality of communication in video conference consultations.

Anita Amundsen, Marita Jacobsen, Tone Nordøy

### Background

The aim of this study is to improve the health service to cancer patients living in remote areas. This study is designed to investigate the feasibility of tele oncology in the form of video conference consultations for cancer patients living in areas without oncologists.

Video conferences consultations have been investigated in several fields of specialist care. In oncology, videoconference consultations are well received by cancer patients and have proven cost-effective. Several aspects of video conference consultations have been studied, but there seems to be a lack of studies addressing aspects of communication during this type of consultations.

One may assume that the physical distance and the limitation of technology may alter the quality of communication. Knowledge of such potential effects will be important in the development and implementation of a tele oncology service.

### Method

This part of the study will be designed as a randomized controlled trial (RCT). Participants will be oncology patients from Finnmark attending their first evaluation consultation. Patients will be randomized to receive consultation by video conference or face-to-face. This consultation will be video recorded, transcribed and analyzed.

Primary endpoint:

Difference in frequency and type of questions from patients/caregivers.

Secondary endpoint:

Difference in frequency of patients' emotional cues and concerns and doctors response. Difference in anxiety/depression/health related quality of life.

Difference in satisfaction with the consultation and information retrieved.

### Discussion

Video conference enables patients (and eventual caregivers) living in remote areas to meet with oncologist without physically going to a specialist cancer center. If beneficial to oncology patients, a flexible tele oncology service probably can provide video conference consultation on a more day-to-day basis. Knowledge of potential effects on communication will be important when considering the development and implementation of this type of tele oncology service.

# Use of virtual reality to practice team communication

### Aslak Steinsbekk, Ekaterina Prasolova-Førland

### Background

Medical students seldom get the chance to practice in hospital setting with students from other professions and they seldom see the whole patient trajectory during clinical rotation. Virtual reality can give students more time on task and prepare them for direct patient contact and clinical rotation.

#### Summary of work

We have made a virtual part of a hospital in Second life (NTNU island) with patient room, meeting room, operating theatre etc. Medical and nursing students in groups of 4 to 6 practice roleplay both sitting apart with only a PC and sitting together using 3D/virtual googles.

#### Summary of results

Students reported that they found the virtual reality to mirror real life and all agreed that they had learned about the necessity of clear and to the point communication. Several experienced nausea from using the googles over time.

#### Discussion

Some of the assets of virtual reality roleplay is the possibility for repetitions and that it can be used at any time, making it independent of scheduled teaching. The greatest challenge is to make realistic cases that mirrors what the student will meet e.g. on clinical rotation.

#### Conclusion

Using a geriatric case (spine fracture and confusion, long trajectory over weeks) and a gynecological case (extrauterine pregnancy, subacute trajectory over hours) made it possible to demonstrate the usefulness of virtual reality in practicing team communication along different stages of the whole patient trajectory.

#### Take-home Message

Spending relative little resources on making the virtual reality set up in Second life, made it possible to give students experience of team communication through different patient trajectories. The challenge of introducing virtual reality is in making good cases.

# An explorative study of inefficiency in medical encounters – towards the development of an assessment framework

Daniel O. Ilstad (1), Pål Gulbrandsen (1,2), Eirik H. Ofstad (3)

1 The Research Centre, Akershus University Hospital, Lørenskog, Norway

2 Institute of Clinical Medicine, University of Oslo, Oslo, Norway

3 Department of Medicine, Nordland Hospital Trust, Bodø, Norway

**Introduction:** In a busy clinical workday, effective patient-physician communication is vital to patients, physicians and the health care system. Most of the previous research that has described and tested elements of effective communication in patient-physician-encounters have been performed in general practice. In a review of the field, Mauksch and colleagues have described a framework consisting of ten different skills or actions that might enhance or hamper efficiency. Few studies have looked at the identification of inefficient elements of patient-physician communication. Building on the review by Mauksch, we have performed an updated literature search of the field and worked to develop an assessment framework to identify inefficient communication in medical encounters.

**Objective:** To identify, classify and measure the time spent on inefficient communication in encounters between patients and physicians in different hospital settings.

**Material and methods:** A qualitative study of video-recorded patient-physician encounters. A total of 66 encounters will be analyzed from a corpus of 372 encounters from 17 different hospital specialties, including 58 hospital physicians. The first ten encounters were selected from a randomized list of encounters – and from these elements of efficient and inefficient clinical communication were described. The next 15 videos were selected based on previous analyses of the encounters which gave reason to anticipate that examples of efficient or inefficient communication would be present. Another six videos were randomly selected to check the validity of findings in previous videos. And finally – to analyze at least one video from each of the participating physicians – 41 videos were identified based on previous analyses of the encounters.

We will present: The development of a framework assessing inefficient communication in medical encounters. We will describe if and how the elements of our assessment framework are present in our material of 66 encounters and aim to present measurements of how much time they amount to.

### **Questions for discussion:**

- 1. Is a framework assessing inefficiency in medical encounters possible and meaningful to develop?
- 2. What do you think of the elements we have decided to include in our framework?
- 3. Is it possible to measure how much time is spent on inefficient communication and do the elements of our framework allow for time measurements?

Reference: Mauksch et al. Relationship, communication, and efficiency in the medical encounter: creating a clinical model from a literature review. 2008 Archives of Internal Medicine

# Coding Communication related to Shared Decision Making: Normative and Descriptive Challenges

### Wynne Callon, BA and Mary Catherine Beach, MD, MPH

Shared decision making (SDM) has become a popular focus of discussion in the health care community, with the development of several communication coding systems and debate about what SDM ought to entail.

To understand the variety of ways in which SDM does (or does not) occur, we analyzed dialogues in three very different clinical contexts: (1) Hematology specialists and their patients with sickle cell disease discussing hydroxyurea initiation; (2) HIV primary care providers and their patients discussing antiretroviral therapy initiation; (3) surgeons and parents of children with sleep-disordered breathing discussing the possibility of elective tonsillectomy.

Through this work we have become increasingly cognizant of the many nuances in coding communication and the difficulty of applying a one-size-fits-all framework to SDM dialogue. Recognizing this, we took a step back to compare 4 prominent SDM models – Braddock, OPTION, MAPPIN'SDM, and Clayman's Integrative Model. In doing so, we paid special attention to the similarities and differences between the models, and thought critically what elements of shared decision making made the most sense in light of the observed communication within the three clinical scenarios.

This iterative process of coding, comparing, and discussing elements of SDM has raised questions for us regarding the scope of SDM and what lies within and beyond that scope. Our current analysis aims to distinguish how to define what *did* happen in an encounter with what *should have* happened. In our presentation, we will attempt to demonstrate and get input around a novel set of issues including: (1) the potential role of socioemotional communication in SDM conversations, (2) the role of prescriptive communication (making clear recommendations) vs. exhibiting equipoise, including when and why the discussion of the option to 'do nothing' is warranted, and (3) how to incorporate quality of how information is conveyed (use of jargon, provider monologues, etc).

### Session B3 – Health literacy and information needs

# Assessing levels and correlates of health literacy (HL) in Norwegian childhood, adolescent and young adult cancer survivors (CAYACS) – The NOR-CAYACS study.

Von Possel, N (1); Mellblom, AV (1); Finset, A (1); Lie, HC (1,2)

<sup>1</sup> Department of Behavioural Sciences in Medicine, Faculty of Medicine, University of Oslo, Norway

<sup>2</sup> National Advisory Unit on Late Effects after Cancer Treatment, Oslo University Hospital, Radiumhospitalet, Norway

**Background.** CAYACS face elevated risks of severe health problems, late effects, in the wake of their cancer treatments. Risk-stratified lifelong follow-up care and / or health self-management are expected to reduce the risk and negative consequences of such late effects. Thus, to be empowered and motivated to manage their health as recommended in terms of lifestyle choices, self-monitoring and follow-up care attendance, CAYACS need to be educated about their risks of late effects and recommended health-related behavior. To be able to target and tailor such patient education according to individual capacities, survivors' health literacy (HL) levels should be taken into account. The main aims of this study are to validate a self-report HL measurement tool for use in a Norwegian CAYACS population and to investigate HL levels and associated factors among CAYACS.

**Methods.** *Sample:* Representative samples of six diagnostic groups of young cancer survivors with good prognosis, long life-expectancy and high risk for late effects were identified through the Norwegian Cancer Registry (NCR) (N = 5567; diagnosed before age 40, current age: 18-65 years; diagnosed: 1985-2009; diagnosis: childhood, breast and colorectal cancer; malignant melanoma; leukemia and lymphomas). They were mailed the study questionnaire, which included the Health Care subscale of the HLS-EU-Q47 as a HL measure (HLS-HC). The HLS-HC was translated into Norwegian following standard translation procedures. Factors potentially associated to HL levels were also measured: demographic and disease variables, quality of life and mental distress, information seeking, needs and satisfaction.

**Preliminary results.** Preliminary data analysis indicates sound psychometric properties of the translated HLS-HC (Cronbach's a = .91, item distributions and inter-item correlations largely in accordance with the original HLS-EU). Factor analysis implies content-based sub-dimensions of the HL construct (e.g. making sense of doctor's instructions, what to do in an emergency). On a scale from 0 (poorest possible) to 50 (best possible), HL scores were categorized into "inadequate" (0-25), "problematic" (>25-33), "sufficient" (>33-42) and "excellent" (>42-50) as according to scoring instructions. 41.5% of the CAYACS were categorized as having limited (inadequate or problematic) HL. HL scores vary slightly by sex (with better results for female (mean=35.2) compared to male survivors (mean=34.4)) and diagnosis (with best results for leukemia and melanoma survivors (mean= 35.8 for both) and poorest results for breast cancer and lymphoma survivors (mean= 34.4 for both)). Findings of further factors associated with HL will be presented. It would also be interesting to discuss the possible implications of the findings on HL screening practices as well as patient education strategies.

# Predictors of information needs, satisfaction and information seeking behaviour among Childhood, Adolescent and Young Adult Cancer Survivors (CAYACS): The NOR-CAYACS study – preliminary results.

Lie, HC (1,2); Loge, JH (2,3); Ruud, E (4); Finset, A (2); Fosså, SD (1); Mellblom, AV(2) & CE Kiserud (3)

<sup>1</sup> National Advisory Unit on Late Effects after Cancer Treatment, Oslo University Hospital, Radiumhospitalet, Norway

<sup>2</sup> Department of Behavioural Sciences in Medicine, Faculty of Medicine, University of Oslo, Norway

<sup>3</sup> Regional Centre for Excellence in Palliative Care, Oslo University Hospital, 0310 Oslo, Norway.

<sup>4</sup>Department of Paediatric Medicine, Oslo University Hospital, Rikshospitalet, Norway.

**Background.** CAYACS face persistent higher rates of morbidity and of early mortality compared to the general population due to treatment-related health problems (late effects). They need information about their risks of late effects to make informed lifestyle choices, to seek timely medical advice and to communicate their health risks to health care personnel without knowledge of late effects. Yet the majority of survivors lack such knowledge. One of the main aims of the NOR-CAYCAS study is to investigate CAYACS knowledge of, need and preferences for, information about late effects in a national representative cohort and factors associated with these.

**Methods.** *Sample*: Six diagnostic groups of relatively young cancer survivors with good prognosis, long life-expectancy and relatively high risk for late effects have been identified through the Norwegian Cancer Registry and have been mailed the questionnaire (n=5567; diagnosed before age 40, current age: 18-65 years; diagnosed: 1985-2009; diagnosis: Childhood- ; Breast- and Colorectal-cancer; Malignant melanoma; Leukemia and Lymphomas)

| Potential explanatory variables: | Outcome variables:                          |
|----------------------------------|---|
| Disease-related variables        | • Self-reported information seeking         |
| Socio-demographics               | behaviour                                   |
| Health Literacy                  | • Perceived need for information about late |
| • Quality of life (Sf-12)        | effects                                     |
| • Neuroticism (Eysenck)          | • Satisfaction with information received    |
| • Depression (PHQ9)              |   |
| Anxiety (HADS)                   |   |

**Status of Study.** Data-collection is completed. Preliminary analyses indicate that about half of the survivors have actively tried to find information about late effects, mainly on the internet and from their oncologist. The information rated as most important to receive was: Information about possible physical late effects; possible psychological late effects; the cancer disease and lifestyle advice. Models of factors associated with individual preferences for type of and satisfaction with information as well as with information seeking behaviour will be presented. I would also like the opportunity to discuss possible implications for information provisioning and patient education in clinical follow-up care of young cancer survivors.

## Session A4 – New methods

# Accounting for patients' preferences in studying treatment effectiveness; the relative value of a patient preference trial as a way to effectuate personalized health care

### Sandra van Dulmen; s.vandulmen@nivel.nl

Prevailing paradigms in health care policy and practice demand increased patient participation. This is reflected in more self-management, shared decision-making and empowered interactions. The patient voice counts and so do his preferences, needs and values, i.e. the building blocks to person-centered or personalized health care. Interestingly, such a democratic approach does not yet count for study designs; a RCT is still considered the gold standard for testing treatment effectiveness. In a traditional RCT there is no place for treatment preferences. RCTs make an assumption of clinical equipoise and provide research evidence of group efficacy. This could explain disappointing recruitment rates, high dropout and less clinically valid results. A specific preference for (or against) treatments under study may moderate treatment efficacy, especially in case of highly preference-sensitive interventions where motivation may impact outcome. If preference is an effect modifier then a treatment may be maximally effective for those who prefer it (being more motivated) and minimally for those who do not. Hence, accounting for patients' preferences in studying treatment effectiveness can boost the widely pursued personalized healthcare paradigm. To account for patients' treatment preferences, patient preference trials (PPTs) have been proposed. PPT-based studies suggest that allowing patients their preferred treatment promotes recruitment and outcomes. Yet, it is questionable if every patient is capable to express a preference. Moreover, various PPT designs exist that differ in randomization and moment of choice. It is unclear which subtype is most person-centered; the opportunity to choose may already enhance one's sense of control and thereby increase self-efficacy and active participation resulting in enhanced outcomes. During the OCHER meeting I want to discuss the idea of contrasting outcomes of traditional RCTs with those of PPTs to examine the added value of accounting for patient preferences.

# Application of the Decision Identification and Classification Taxonomy for Use in Medicine (DICTUM) on clinical decisions in optometric practice

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### Background

Clinical decisions are key outcomes of vision care. The DICTUM framework developed for use in medicine consist of ten topical categories and three temporal categories allowing identification and classification of a clinically relevant decision, defined as "a verbal statement committing to a particular course of clinically relevant action and/or statement concerning the patient's health that carries meaning and weight because it is said by a medical expert". The aim of this study is to evaluate the application of the DICTUM framework to the allied profession of optometry and to explore whether the same categories of clinical decision applies to medicine and optometry.

### Method

We will code clinical decisions in optometric practice using the DICTUM framework. The framework will be applied to a sample of 45 optometrist encounters, including 45 patients and 11 optometrists. Of the patients 22 were female and 23 male, mean age was 65 years (range 46-91). Of the participating optometrists seven were female and four male. The number of encounters for each optometrist ranged from one to eight.

### Results

We will present results for categories and subcategories of clinical decisions made in optometric practice and compare these with clinical decisions made in medicine. Further, new categories and/or subcategories specific to decisions in optometric practice will be described.

### **Points for discussion**

- 1. Can the DICTUM framework be used to describe clinical-decision making in optometry?
  - a. Generic clinical decisions categories
  - b. Profession specific clinical decision categories
- 2. Can the DICTUM framework be used to identify decisions relevant for patient involvement in optometric decision-making?

### **Session B4 – Conversation analysis**

# Dementia and communication problems in a first and second language

### Jan Svennevig, Anne Marie Dalby Landmark and Marianne Lind

In this presentation, we explore naming problems and strategies used to cope with these by one bilingual speaker with Alzheimer's disease. The study shows that speech production problems may vary considerably in the first language (L1) compared to the second language (L2). In the English (L1) conversation, the speaker's main problem is accessing specific lexical items, often information-carrying, low frequency nouns that can fit into a fully developed syntactic construction. In this conversation he is also able to use various strategies, such as circumlocution, explanation of meaning and use of semantically less informative proxy nouns ('thing', 'guy'), to remediate his word-finding problems. In the Norwegian (L2) conversation, on the other hand, the main problem is related more to accessing and/or constructing the syntactic frame with which the information-carrying lexical items are integrated. In this conversation he is also less able to use remediating strategies. These different manifestations of speech production problems in English and Norwegian have implications for which strategies his interlocutors can use to scaffold his contributions and assist in the search for lexical items. The more fully developed grammatical structure in the English conversation, limit the range of candidate formulations that the interlocutors can reasonably make. The result is that the interlocutors are more active in assisting the speaker in his production and in displaying their understanding in the English conversation.

The results above are based on interviews conducted one year after diagnosis of probable Alzheimer's disease. We will complement the study with analysis of interviews conducted 2.5 years after diagnosis and discuss the differences observed in language and interaction in L1 and L2.

# Addressing psychosocial distress? A CA analysis of doctor-patient interaction with the Distress Thermometer during follow-up oncology consultations

### Manon van der Laaken

There is a widely-shared consensus that in follow-up cancer care, patients do not just need their physicians to heal them, they also require them to address their psychosocial concerns: their stress, their fears and their uncertainties (see e.g. Arora, 2003). However, many studies indicate that physicians tend to limit themselves to biomedical concerns in their consultations, and avoid psychosocial topics (e.g., Beach et al., 2005). Screening instruments such as the Distress Thermometer and Problem List, which measure the psychosocial distress of cancer patients, are increasingly being used as discussion prompts to introduce the discussion of psychosocial problems during the consultation. They have been shown to increase the number of psychosocial issues discussed during consultations, and physician awareness of them (Detmar et al., 2002). However, it is unclear whether such tools help to achieve shared understanding between doctor and patient of the goals of treatment and treatment success. Moreover, they do not seem to lead to a higher decrease in "anxiety, depression and perceived needs" compared to control patients (Boyes et al., 2006: 169), nor do they seem to lead to changes in decision making: "in reality, HRQoL issues [Health Related Quality of Life issues, MvdL] tend to be overruled by biomedical factors" (Greenhalgh, Long & Flynn, 2005: 840). Further research is therefore warranted into whether and how the Distress Thermometer can contribute to the inclusion of psychosocial problems in doctor-patient interaction, the development of shared understanding of psychosocial problems between doctor and patient, and their inclusion in the decision-making process. The current presentation will use a CA approach to analyse how doctors make use of the Distress Thermometer and whether and how this results in doctor-patient discussion of psychosocial issues and their treatment.

## **Session A6 – Coding and measuring emotions**

# Exploring positive emotions expressed by older people in home care

### Hilde Eide (1), Lena Heyn (2)

(1) Professor, Science Centre Health and Technology, University College of Southeast Norway (2) Associate professor, Institute of Nursing and Health Sciences, University College of Southeast Norway (from 1.1 2017)

### Abstract

Affect is described as higher order categories of positive and negative emotions producing changes in peoples' thoughts, actions and physiological responses. Negative emotions narrow individuals' momentary thought–action repertoires while positive emotions broaden and expand the range of thoughts and actions. Positive emotions increase well-being in the moment by triggering upward spirals of cognitions and actions improving the capacity to cope with adversities experienced in the course of daily living. Thus, being able to mobilizing positive emotions is an important part of resilience and high-resilience individuals report more positive emotions, but most of all because it triggers a multitude of benefits pr. see on a cognitive as well as on a physiological level. How this applies to how older persons' communicate while receiving homecare is not explored.

The aim of this study is to develop a protocol for coding positive emotions and perform a pilot study.

We will start with open coding inspired by lists measuring positive affect as PANAS (adjectives for positive affect are interested, strong, inspired, attentive, enthusiastic, proud, alert, lively, active and determined) and Barbara Fredrikson's positive affect areas:

- 1. amused, fun-loving, or silly
- 2. awe, wonder, or amazement
- 3. grateful, appreciative, or thankful
- 4. hopeful, optimistic, or encouraged
- 5. inspired, uplifted, or elevated
- 6. interested, alert, or curious
- 7. joyful, glad, or happy
- 8. love, closeness, or trust
- 9. proud, confident, or self-assured
- 10. serene, content, or peaceful

The study will explore expressions of positive emotions in audio-recordings from the international research project on person-centred communication with older people receiving healthcare at home (COMHOME, RCN no. 226537). We will select recordings strategically from the 196 visits with 48 older persons in Norwegian home care.

As this is a study under development we would like input on the design we have developed so far based on our presentation of experiences with coding the tapes.

# **Response Pattern Scale 2.0**

### Mathias Tranberg

Ulla Holm created an instrument to measure empathic communication, as it was expressed through a performance test, the Response Pattern Scale. This test was validated and proved to be useful for measuring empathy and professional attitude across different professions. It also showed a correlation between length of training and expressed empathy. The scale focused on the response to a client's emotional reaction and statements. It consisted of four videotaped situations where a client makes a statement to a professional helper who is out of view from the camera. The subject was asked to write down, word for word, what he/she would respond to the client. The response was rated using a scoring template and produced a quantitative as well as a qualitative measure.

This test could be useful as an outcome measure for interventions intended to improve communication skills in health care providers. The problem is that the video recordings are out-of-date. After consulting Ulla Holm and reviewing the recording together with her we have made new scenes and plan to record them with

- 1. Psychologists as actors
- 2. Actors

Psychologist are the group who received the highest score of all professionals who were tested with the Response Pattern Scale. The hypothesis is that psychologists have awareness of conflicting emotions and can portray them in a convincing way. Actors, can be assumed to be very skilled at portraying emotions, to the extent they understand what conflicting emotions are present.

We will test students from medical school. One group will be tested with the video recordings by psychologists and one group will be tested with the actors. The results will validate the two tests.

The result will be a validated performance test that is easy to administer and gives a both qualitative and quantitative measure.

# **Session B6 – Cross-cultural challenges**

# **Doctor-patient communication in Ethiopia and Uganda**

### Nataliya Berbyuk Lindström, Jennifer Månsson, Betty Girma Kebede

Doctor-patient communication is essential for quality of health care. Little has been done about doctor-patient communication in Africa in general, and in Uganda and Ethiopia in particular. In this study, we describe and analyze how doctors, cancer patients and family caregivers experience their communication concerning a) general experiences and satisfaction; b) breaking bad news to cancer patients and their family caregivers and the ways patients and family caregivers receive bad news, c) language usage during consultation meetings, and d) the cultural issues that influence patients' health seeking behaviors in Uganda and Ethiopia. Second, we analyze public awareness about cancer diseases in both countries.

Methods: both qualitative and quantitative methods were used. In both countries, 27 doctors, 86 patients, 43 family caregivers were interviewed and 46 doctor-patient-family caregiver interaction video recordings were made. We transcribed all the video recordings and part of the interviews. In addition, 284 questionnaires were analyzed. We used simple descriptive statistics.

Results: Doctors experience challenges associated with influx of patients, language barriers, illiteracy levels, lack of cancer awareness, inabilities/unwillingness of patients and family caregivers to ask questions. Patients and family caregivers are not satisfied with the information about cancer and the manner in which doctors give them information, complain about nurses' attitudes and physical environment. There is great need of information about cancer disease. Public perception about cancer is low in both countries.

# Migration background and experience with colorectal cancer related health care

### Marja Leonhardt

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Background: Currently 19.1 % of the German population has a migrant background. This number is not reflected in health research as it is difficult to determine whether a person has a migrant background or not. However, the existing few studies on migrant health show that migrants are faced with restrictions regarding health care due to communication problems, a lack of information and distinct health literacy. Colorectal cancer (CRC) is the second most common tumor disease – regardless of gender – in Germany. The median age by diagnosis is 71 in men and 75 in woman – just the age of the first generation migrants.

Object of the study: To ensure an equal health care and therapy for colorectal cancer patients it is essential to identify their expectations and possible disparities between migrants and nonmigrants.

Methods: An established questionnaire used previously in a study of gynecological cancer patients was adapted for CRC and supplemented with items to determine the migrant background, translated into Arabic, Turkish and Russian and sent out to 1.600 patients who have been registered in the Charité Cancer Register from 2004-2014. The outcome indicator is

'health care experience' concerning (1) medical consultation, (2) the therapy and (3) the hospital stay; explanatory variables are migrant background but also age, gender, mother tongue,

occupation, current discomfort and current treatment. Items regarding the information behavior

are reported. Following descriptive statistics, factor analysis is conducted to compute the outcome variables. Differences between migrants and non-migrants are analyzed using Mann-Whitney-U tests and regression analyses.

Status of study: 522 responded questionnaires can be used for analyses. There is no major difference between migrants and non-migrants regarding the 'health care experience' but a migration background has a moderating effect on how positive health care experience is evaluated. In the next step, items regarding the information behavior have to be analyzed. I would like to discuss the difficulty of conducting surveys addressing patients with different cultural and language background.

## **Session A7 – Unpleasant information**

# **Communication of unpleasant information**

### Stine Løkkeberg

This thesis focuses on the communicating of unpleasant information in six experimental studies. Specifically, the experimental studies investigate how withholding and/or disclosing unpleasant information is appraised by the communicator in three various ways (degree of severity, concern for one's self-image and concern for one's social-image in the eyes of others), how these appraisals relate to three core feelings (felt rejection, felt inferiority and felt shame), and how these explain two main motivations (wanting to distance oneself from the other, wanting to repair the social bond with the other) across various social bonds (both private and professional). In the two first studies it was found that disclosing unpleasant information caused the communicator to report significantly less distress (lower levels of appraisals, feelings and motivations) compared to when the communicator withheld the unpleasant information. In studies three to six, it was found that, when communicators disclosed the unpleasant information, the prototypical communications strategy of being person-centred caused the communicator to feel significantly less distress (lower levels of appraisals, feelings and responses) than if two other prototypical ways of communicating were used (the fully direct strategy and the fully indirect strategy). In all six studies, I found that the motivation of wanting to distance oneself from the other was explained by a "concern for one's social-image  $\rightarrow$  felt rejection" pathway, while the motivation to repair the social bond with the other was explained by a "concern for one's self-image  $\rightarrow$  felt shame" pathway. The thesis argues the importance of disclosing the unpleasant information and of disclosing it in a person-centred way.

# **Communicative guidelines for unpleasant information**

### Stine Løkkeberg

Even though professional helpers often respond that they feel unwell when they have to communicate unpleasant information to a patient (e.g., a message of serious illness), there exist few medical communicative guidelines that can aid them when they need to communicate it. This is quite a paradox as long as there exist several that focus on how the helper can deal with the patients' emotional experiences in such instances. Hence, the medical communicative guidelines have actually failed to address the helpers' role in communication of unpleasant information. We therefore argue the need to provide the helper with guidelines that can aid them when they communicate unpleasant information to their patients so they can understand when and how professional helpers appraise the communication of negative information as distressing, what emotions they will typically feel and what coping strategies are likely to follow in its response. Hence, we suggest a model that can aid the professional helpers in their role of being a communicator of unpleasant information.

## Session B7 – Shared decision-making

# Patients' and GPs' renouncement of responsibility in decision making about cardiovascular preventive treatments.

### Josabeth Hultberg

Cardiovascular preventive drugs are commonly and increasingly prescribed in primary care. The decision making process about preventive treatments involve an element of risk communication, at least in theory.

In order to study this decision making process in clinical practice I have audiorecorded 80 patient-doctor encounters from Swedish primary care. The corpus amounts to 24 hours of recordings. 36 of the encounters involve talk about cardiovascular preventive drug treatments.

A paper is submitted about different formats of patient resistance to treatment proposals, displaying their agency in decision making. During that analysis we noted the renouncement of responsibility from both patients and GPs in the treatment negotiation sequences. Patients' explicit deferral to doctors' deontic authority has been described by Lindström & Weatherall who propose further work on what such statements accomplish (1). Dalby Landmark et al discuss instances of mutual renouncement of responsibility where the patient insists on the physician's deontic authority and the physician insists on the patient's deontic authority resulting in situations where both parties avoid the full responsibility for the decision (2). This stands in contrast to the common assumption in literature about patient centredness, where the allocation of responsibility is often portrayed as a struggle between patients and doctors to claim power and decisional responsibility.

Preliminary findings include the use of pronouns - particularly ambiguous "we" and the swedish "man" (one) - to accomplish distancing from responsibility. Physicians referral to "one", as in the medical community in general, occurs in response both to patients resistance to treatment proposals and to their renouncement of responsibility for decision making.

The present project aims to further explore how renouncement of responsibility for decisions is accomplished in treatment negotiations about cardiovascular preventive drugs between patients and general practitioners.

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# Training health professionals in Shared Decision Making: Development and evaluation of a training course based on Participatory Action Research

### Jette Ammentorp

Professor, Research Manager. Health Services Research Unit Lillebaelt Hospital / IRS University of Southern Denmark

Like many other initiatives also focusing on Shared Decision Making (SDM); training programs specifically aimed at improving health professionals' skills in relation to SDM have been growing rapidly in number over the past years. However, variation of both the content and the duration of these programs may be a reflection of the fact that SDM is a complex concept which is difficult to fully get a grip on. Consequently, knowledge on for example specific skills required of the health professionals in order to meet the needs and wishes of the patient is lacking.

Based on our experiences from developing and implementing the mandatory and basic communication program 'Clear Cut Communication with patients', and on an ongoing discussion about the concept of SDM, we decided to involve both patients, clinicians, communication trainers and researchers in the development and evaluation of a one-day training program in SDM.

Inspired by Participatory Action Research (PAR) we have used methods like theater workshops, scientific workshops, test-courses, focus-groups and questionnaires to develop and evaluate the course.

At OCHER 2017 the experiences from this process will be presented and participants will be invited to discuss the advantages and disadvantages of using this research approach (PAR) and involved methods.

# **Session A8 - Interventions**

# Can we improve shared decision making for multiple sclerosis patients concerning treatment choices: A randomized controlled trial

### Jenny Nordfalk

The goal of this project is to research whether it is possible to improve patients' understanding and memory, and thus involvement in decision making, by teaching doctors highly specific changes in communication style, in the specific and complex situation of initiating second line MS treatment.

Multiple sclerosis (MS) is an unpredictable disease, and the choices concerning treatment are difficult; with insecurity both when it comes to treatment effect and side effects. So far, there has not been conducted adequate research to decide what sufficient information is, nor how to optimally support the patient, in the course of choosing a treatment. We have as our pilot, made video recordings of IRL (in real life) MS consultations, followed by patient interviews. We had high aims of wanting to set up a consensus based fact sheet, involving ethic and neurologic expertise in addition to the view of the MS patients. The fact sheet was supposed to provide an overview of what kind of information a neurologist *must, should*, and *could* give to these patients, but found it impossible due to the fact that they are all so different in personality, educational level, emotional distress level and how much they want to be part of making a decision.

Our intervention study contains 34 videotaped consultations, in which 16 different neurologists have met real MS-patients who all simulate the same given case. After seeing one patient each, the doctors participated in a short, but customized communication course, before seeing another patient each. After each consultation, the patients are interviewed to see how much they remember out of the facts the doctors have just given them. We are also trying to measure how much they understand, which is a challenge.

# Communication intervention for pediatricians at follow-up consultations with adolescent cancer survivors. – Planning phase

### Anneli Mellblom, Hanne Lie, Ellen Ruud, Arnstein Finset

Introduction

After childhood cancer it is routine to have follow-up at the pediatric department for 10 years or until the patient are 18 years. The goal of the follow-up is to monitor relapse, late effects and to inform the patient. There is little research on the actual content and clinical communication practices of follow-up consultations after childhood cancer. A study from our research group shows that the structure and content of follow-up consultations vary widely between pediatricians. The standard consultation lasts approximately 30 minutes; including a patient interview and a physical examination. Half of the studied consultations contained emotional concerns and in 85% of the consultation there were talk about late effect (treatment-related health problems) topics with varied degree of information giving. Communication with adolescent survivors after cancer treatment is a special challenge both due to transition to adult health care and that the patients need to learn how to take responsibility of their health. There are no organized long term follow-up after childhood cancer, and many late effects appear decades after treatment completion, therefore are knowledge of ones risk is of great importance. Methods

# Using observational data from our previous study from video-recordings from follow-up consultations, existing guidelines and expert opinions (both from clinicians and communication experts) we have developed a consultation model for the communication at follow-up consultations for adolescent cancer survivor, the model contains seven

communication skills.

The intervention will be organized in 3 steps: First we will collect baseline video-recordings of follow-up consultation between adolescent cancer survivor (12-18 years old) and their pediatrician. Secondly is the intervention where we first will teach the seven skills to the pediatricians in a lecture, followed by a group discussion. We will also offer individual coaching using the baseline videos. Thirdly we will collect new videos from follow-up consultations to test for the effect of the intervention.

# Predictors of nursing staffs' responses that opens up for exploring emotions expressed by older people in home care

PhD candidate Linda Hafskjold, University College of Southeast Norway Associate professor Vibeke Sundling, University College of Southeast Norway Professor Sandra van Dulmen, NIVEL; Radboud University Medical Center; Nijmegen, University College of Southeast Norway

Professor Hilde Eide, University College of Southeast Norway

Background

The study is part of an international research project on person-centred communication with older people receiving healthcare at home (COMHOME). In this particular study, we explore the communication between older people and nursing staff (registered nurses (RN) and nurse assistants (NA)).

The aims of this study are to: 1) describe features of nursing staffs' responses opening up for further disclosure of emotional distress communicated by older people, and 2) identify predictors that facilitate these types of responses.

Sample and method

Audio recordings of 196 visits with 48 older persons and 16 RNs and 17 NAs in Norwegian home care were analyzed with Verona Coding Definitions of Emotional Sequences (VR-CoDES).

Three sum categories of cues/concerns were constructed from theory to enable differentiation between different expressions of distress:

1. expressions of emotion (concern and cue a, f and g)

2. expressions about hidden concerns related to internal or physiological state (cue b and c)

3. neutral expressions that could represent an emotion based on contextual hints in the communication (cue d and e)

A dependent variable, emotion response, representing RN/NAs responses opening up for further disclosure of the emotion, was constructed by collapsing response categories of the VR-CoDES. Emotion response included, providing space allowing further exploration of the emotion with a) explicit reference to the emotion (three codes), and b) non-explicit reference to the emotion (five codes), and served as a binary variable in a logistic regression analysis. Results

Patient expressions with a clear or vague emotional reference and cues/concerns elicited by the RN/NA independently predict a response supporting further disclosure of emotion. Expressions elicited by patients, are more frequently met by a response not focusing on the emotion.

Points for discussion

- Comments on the conceptual framework used for this analysis
- Feedback on the statistical method

# Responses to older persons' emotional expressions during home care visits in Sweden.

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**Background:** Communication is a basic competence in health care. With few exceptions, little is known about the communication of caring encounters in the homes of older people, and health care providers' responses to older persons' emotional expressions.

**Aim:** The aim was to describe registered nurses' and nurse assistants' responses to older persons' emotional expressions during home care visits.

**Method:** In this study data were gathered on 188 audio-recorded home care visits and analysed with the VR-CoDES. There were 20 nurse assistants (NA) and 11 registered nurses (RN) participating together with 81 older persons receiving home care. The elicitations and the responses (n=316) on older persons emotional expressions in the verbal communication were coded.

**Results:** In total, most responses provided to older persons emotional expressions were nonexplicit (n= 294), and rarely explicit (n=22). Furthermore, responses that provide space (n=237) for further disclosure were more often used by the nursing staff than responses that reduced space (n=79). Most common responses, providing space for further disclosure, were back-channelling (31%) followed by active invitations (19%). The responses that provided space were also more frequently used when the nursing staff had elicited the older persons emotional expression (69%) compared to when the older persons themselves elicited such expressions (31%).

Further results will be presented and examples given on responses.

**Discussion:** Responses providing space versus reducing space will be discussed in relation to person centered communication.

### **Session A9 – Experimental approaches**

# Use of Question Prompt Lists in arranged consultations with Type 2 Diabetes patients: Potential effects on satisfaction, recall and psychophysiological stress responses

### Erik Holt and Arnstein Finset, Dept. of Behavioural Sciences in Medicine, UiO

*Background:* The question whether it matters if the patient to be prepared for the consultation or not has been studied by using a Question Prompt Lists (QPL) before consultations with doctors, in particular in cancer care. So far no studies are found investigating the effect if QPLs on using psychophysiological variables.

*Purpose:* To investigate the effect of presenting patients with Type 2 Diabetes (T2D) with a QPL before arranged consultations on patient satisfaction, recall anxiety and psychophysiological activation.

*Method:* Two groups of patients with T2D will be given an arranged consultation with a physician in laboratory. Each group will consist of people of age 60 - 80, of both sexes. The intervention group will be given a Question Prompt List (QPL) before an arranged consultation. The Control group will receive the consultation only.

An Australian QPL for cancer patients (no QPL found for GP use) translated to Norwegian by A. Amundsen et al., UiT will be revised after focus group interviews with patients recruited through the Diabetes Association in Norway.

A presentation of the plans for the study will be given, and we will open for discussion of the design, methods and feasibility of the proposed study.

# Strengthening Emotional Intelligence through reflective learning: Getting perspective on self and others; taking different action

### Ane Haaland, Debbie Cohen

Introduction: Fast pace and a demanding environment characterizes work in the National Health Service (UK). Doctors and medical students have higher levels of mental ill health than the general population. Emotional and cognitive labour associated with high levels of care can lead to stress, distress and burnout, leading to lower quality of care, increased errors and decreased wellbeing of staff.

Increased health and wellbeing of staff improves safe and effective patient and relationship centred care. Resilience is seen as a necessary skill for healthcare professionals to develop. Emotional intelligence (EI) is an important premise to developing resilience.

### Method

A 6 months programme to strengthen EI as foundation for resilience was implemented with 11 doctors in training in the Wales Deanery (April to October 2016). Self-directed learning through guided observation/reflection tasks was the core method with four three hour workshops using experiential learning methods.

Evaluation pre, midway and post training included quantitative measures: CD-RISC (resilience), SF12 (wellbeing) and qualitative measures: questionnaire, semi-structured interviews and reflective narratives.

### **Results**

All trainees engaged with and completed training. Midway quantitative analysis showed no statistically significant change. Final qualitative analysis showed development of EI competence and awareness across the group. Most recognized vulnerability and insecurity as emotions to be acknowledged and dealt with rather than feared and ignored. Perception of resilience shifted from "toughening up" to understanding and managing emotions with awareness. Many described the importance of acts of kindness and are happier at work. **Discussion**,

The final results will be discussed in full. This training built on a model developed and implemented with 240 doctors and nurses in 8 countries. UK trainees also found the training relevant and important and want to act as champions for dissemination. Training can lead to better mental and physical health, higher job satisfaction and better patient care.

\*Final questionnaires being handed in first week of November; will be analyzed by the end of the year.

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# Language used in Medical Records May Reflect and Perpetuate Stigma and Bias

Mary Catherine Beach (1), Katie O'Conor (1), Somnath Saha (1,2)

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**Background**. Language within medical records may reflect providers' unconscious biases, reveal misconceptions, and convey stigmatizing attitudes from one provider that may influence subsequent providers who care for the patient. We sought to characterize how these negative perspectives might manifest within the language of patient medical records.

**Methods**. We conducted a mixed-methods analysis which utilized review of stigmatizing language frameworks in diverse fields, interviews with medical providers, and discourse analysis of the medical records of 25 patients with sickle cell disease (an excruciatingly painful condition that is commonly stigmatized) who reported experiencing discrimination in the emergency department and 54 patient with sickle cell disease who were admitted to the hospital with pain.

**Results**. We identified four themes that may convey negative perspectives: casting doubt on the validity of patient experience, perpetuating negative stereotypes, blaming a patient for their symptoms, and equating a patient with their disease. Doubt on validity of patient experience is conveyed by juxtaposing patient reports with discrediting comments (*patient reports 10/10 pain but labs are stable*). Negative stereotypes can be perpetuated by highlighting patient comments that convey low education or socioeconomic status (*pt not able to keep food down because "it goes straight through me in the diarrhea"*). Patients are blamed for their condition typically by providers highlighting their nonadherence. Finally, patients are depersonalized with terms that conflate patient with disease identity ("*sickler*" vs. "*woman with sickle cell disease*").

**Conclusions**. Although it is natural for clinicians to have both positive and negative feelings about patients, the effect that these feelings have on how information is transmitted in the medical record may be unrecognized. We suggest that this language be more carefully considered, and potential biases be acknowledged and addressed.

# Development and testing of a mobile app to encourage mobilization of patients' strengths in clinical consultations

### Olöf B. Kristjansdottir, Jelena Mirkovic, Heidi Zangi & Cornelia Ruland

Health-related strengths have been defined as "the repertoire of potentials – internal and external strength qualities in the individual's possession, both innate and acquired – that mobilize positive health behaviors and optimal health/wellness outcomes." Capitalizing on strengths is especially important for people living with chronic illness, where management of the condition is largely based on their own health behavior and self-management efforts. Despite the importance of personal health-related strengths, they may still be a neglected resource in the health care of persons with chronic illnesses.

The purpose of the study is to develop and pilot test a mobile app for patients aiming to encourage reflection of and dialog about ones strengths with healthcare provider. During development we used a person-centered design approach and included end-users, both patients and heath care providers, during the whole process. To gain user feedback and feature requirements we used methods including interviews and focus groups, workshops, personas and journey map, prototyping and usability testing. So far, in interviews and focus groups with patients with different chronic illnesses (n = 18) and health care providers (n =16) we have gained insights about users needs and challenges the app must address. Iterative phase of low-level paper prototype development and usability testing is planned for late 2016, and programming in early 2017. After the development phase, the app will be pilot tested in a rehabilitation setting at Diakonhjemmet Hospital. In the pilot study we want to explore if and how use of the app affects patients' awareness of strengths and how they are addressed during the consultation.

During the OCHER meeting I would appreciate input about methods to explore potential effects of the app in the pilot study (by analyzing audio files of consultations, using self-report instruments, e.g. on self-efficacy, and positive emotions).

# **New offer – Plenary workshop**

# **Healing Health Communication – moving relationships**

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The dominating biomedical approach to healthcare seems to influence the clinical encounter in a way that favors a focus on medical treatment options. However, greater attention to the emotional and relational dimensions is called for. This is underlined by the growing research in neurobiology and placebo effects showing how relational elements and encouraging communication about treatment activate placebo-like effects that decrease complications and strengthen the immune system.

Our hypothesis is that patients and healthcare professionals possess resources that have not yet been put into play. If these resources can be activated, not only the patients' communicative experience, but also their health, may be improved. Accordingly, we intend to develop communicative interventions that can improve the personal skills of the patients as well as the healthcare professionals. Instead of the traditional division between treatment of disease and care for the patient, the research process will be guided by the main goal: the well-being of the patient. In this context healing is used as a term to describe the practice directed at reverting sick persons back to the highest degree of well-being.

Moving towards a holistic approach requires research that explores new ways of engaging the patients, and the use of innovative methods to explore how to improve their well-being. Consequently, we have launched a research plan with 5 interconnected projects:

### 1. The context of Decision Making

### 2. Training module on "Existential communication"

### 3. Moving the mind through 5Rhythms® – a qualitative study

### 4. Data-guided health coaching (DACOACH)

### **5.** Recording health consultations

To improve the outcome of the projects Participatory Action Research will be used as a method to generate and share knowledge across projects.

At OCHER 2017 we will facilitate an interactive workshop: a discussion of methods and outcomes related to some of the individual projects and the interaction between them.