



***“Present and Future Challenges and Opportunities for  
Ethics in Nursing and Care”***

18<sup>th</sup> Nursing Ethics Conference

3<sup>rd</sup> International Ethics in Care Conference

September 15-16, 2017

Leuven, Belgium

Conference book

**NURSING  
ETHICS**



## Welcome in Leuven

Dear Colleagues,

Welcome to the 18<sup>th</sup> Nursing Ethics Conference and the 3<sup>rd</sup> International Ethics in Care Conference that are jointly organized by the *International Care Ethics Observatory* of the University of Surrey (UK) and the *Centre for Biomedical Ethics and Law* of the University of Leuven (Belgium). This conference is an excellent occasion to reflect on the present and future opportunities and challenges for ethics in nursing and care. Where do we come from? What are the current pathways of ethics in nursing and care? And what will the future bring?

We invite you to share your insights on the conference themes with your colleagues coming from more than 36 countries. The historic city of Leuven, hosting the oldest university of the Low Countries, provides wonderful opportunities to meet each other academically as well as in social activities.

Welcome and enjoy your time in Leuven!

Prof. Dr. Chris Gastmans

Prof. Dr. Bernadette Dierckx de Casterlé

Prof. Dr. Ann Gallagher

### **Nursing interventions about nutrition and hydration in the end of life care: A nursing ethical perspective**

*Beatrice Albanesi*<sup>1</sup> (1), *Maria Grazia De Marinis* (2), *Rosaria Alvaro* (3), *Michela Piredda* (2), *Anna di Noto* (2)

(1) *University of Rome Tor Vergata- Cardiologist Unit Israelite Hospital of Rome, Italy*

(2) *University of Campus Bio-Medico of Rome, Italy*

(3) *University of Rome Tor Vergata, Italy*

Introduction: Nutrition and hydration in the end life care should be consistent with the WHO definition of palliative and end of life care, with the overall goal to improve quality of life (Holmdahl, 2014). Artificial food and fluid administration is one of the most frequently withheld life-sustaining treatments (van der Maas et al. 1996, Groenewoud et al. 2000, Bosshard et al. 2005). As a result, actually, nurses become closely involved in complex ethical decision-making processes concerning artificial administration of food or fluids for these patients (Bryon, 2008).

Aim: The aim of this study will be to conduct a systematic literature review about nursing interventions in end of life care and to describe nurse's ethical dilemma in the decision-making processes during end-of-life care.

Method: Bibliographic search will be performed through six electronic databases. The reference lists of relevant papers will be also examined. The articles retrieved will be critically reviewed.

Results: The inclusion criteria are: articles published from 2000 to 2017. The key-words include, nursing professional autonomy, nursing intervention, nutrition or hydration and ethics or bioethics, and palliative care or care at the end of life.

Discussion: Although their direct impact is limited, nurses play a substantial direct action during decision-making processes. Their function is to be the patient supporters and provide supervision, information and support to patients, families and caregivers.

Conclusion: Nutrition and Hydration are highly important at the end of life, but sometimes the actions and the assistance during this process need great empathy. The expected results are related to: nurses activities on nutrition and hydration administration, to the roles and rules of these activities and at the end to the emotions and the feelings concern on the decision-making process and end of life decisions.

### **Care of the elderly in African communalism in the light of *The Letter to the Elderly 11*: An ethical theological study**

*Onyema Anozie* (1)

(1) *Catholic Institute of West Africa, Port Harcourt, Nigeria.*

It seems plausible that many cultures of the world accept the Judeo-Christian culture contained in the Scriptures. In principle, the saying still holds that what "is good is Good", not because Christians say or

---

<sup>1</sup> **Name:** Name of the author listed in the programme

**Name:** Name of the presenter

do it. On the other hand Christians do or say something because it is human and good. Evidently, the delicate balance of cultural values can only allude to a single fact, namely; that the world is gradually but surely becoming a global village. The fact is that "First was life before what was written". A keen observer will notice a conspicuous factor about the African culture is its adherence to African communalism – an unwritten but lived law. This factor blossoms in all spheres of the African life especially in the care of the elderly. Granted this is a convention, it finds its sustenance in the fourth scriptural command that carries a conditional reward. The command to honor one's parents goes beyond merely biological relationship. In reality, it stretches to all the elderly. To a very high degree, many cultures of the world underscore the importance of respect for the elderly. The importance and fundamental place of this practice is entrenched in the African communalism. In Africa, communalism is a concept that has far-reaching consequences. However, the modern African in the bid to catch up with the rest of the world is in danger of neglecting a core traditional value such as respect and care of the elderly. This article, therefore, wishes to study the ethical overtones of communalism in relation to care of the elderly in Africa, in the light of the John Paul II's *Letter to The Elderly* 11. This article makes a plea to Africans to development structures to sustain foundational values such as care for the elderly.

### **Keys to exemplary professional practice: Code of ethics for nursing and the ethics blueprint**

Laurie Badzek (1)(2), Martha Turner (2)

(1) *University of North Carolina Wilmington, School of Nursing, USA*

(2) *American Nurses Association, USA*

Enhancements in technology including use of the internet and social media resulted in a more inclusive revision process for the American Nurses Association Code of Ethics for Nurses. This process included thousands of nurses across roles and settings in both the assessment of the need for changes and in gathering feedback following revision. The revision model including dissemination as well as the substantive changes in the approved 2015 Code will be discussed.

Facilitation of nurses' understanding of the American Nurses Association (ANA) Code of Ethics for Nurses with Interpretive Statements (2015) along with its application to practice is integral to quality nursing care. Examples that illustrate professional practice challenges centered around major tenets in the Code will be discussed. Accountability, Competency, Respect for Autonomy, Relief of Suffering, Confidentiality, Quality, and Safety are among concepts explicated in the 2015 Code that can be used to demonstrate exemplary practice in healthcare institutions.

Nurses recognize ethics as an expression of values and obligations that inform their practice. Acknowledgement of ethics as a primary obligation of the profession was reflected in an overwhelming online nursing response when ANA declared "2015 the Year of Ethics". Creating an ethical culture is the premise of a national nursing initiative to create an actionable Blueprint for 21st Century Nursing Ethics (JHU, 2014). Knowledge of current ethics initiatives and information in the blueprint can be helpful to hospitals as they "strengthen a culture where nurses and other health professionals are able to practice ethically".

Application of the Code of Ethics by nurses in all roles and in all settings helps practicing nurses make connections between ethical obligations and excellence in clinical care at the bedside. Exemplars of integration of the Code into daily nursing practice through performance evaluation and peer review will be offered as a means to help institutions promote and create a culture of ethical care.

### **A componential emotion approach to moral distress in health care**

*Céline Aurélie Baele (1), Johnny Fontaine (1)*

*(1) Ghent University, Ghent, Belgium*

**Purpose:** Many health carers suffer from 'moral distress' (MD). Most studies on antecedents and outcomes of MD were conducted using the Moral Distress Scale (Corley, Elswick, Gorman, & Clor, 2001). Recently, however, concerns have been raised on MD's empirical basis. Therefore, our purpose is to empirically determine the core features of MD, using a componential emotion approach.

**Methodology:** In a pilot study, 12 semi-structured interviews were conducted. Professionals of different disciplines (e.g. registered nurses, physical therapists, care assistants) were asked to describe their experiences during a critical incident of MD. The transcriptions were coded and analyzed to identify features and situations of MD.

In Study 1, currently (Febr.- May 2017) being conducted, 200 professionals of different settings (hospitals, care homes, psychiatric care, revalidation centres) will be asked to write about a recent incident of MD, followed by an emotion component questionnaire asking about their appraisals, feelings,

**Results:** The pilot study showed that MD has a strong affective component. Apart from anger, participants tended to experience self-conscious or moral emotions (e.g., shame, guilt). Based on these findings, a componential emotion approach was used in Study 1. The pilot study also provided additional input for the questionnaire used in Study 1.

The outcomes of Study 1 may 1) provide us with a broad range of situations provoking MD 2) help determine the key features of the experience of moral distress. This may provide input for the construction of a context-independent instrument for the detection of MD, useful in the context of risk-analysis.

**Limitations:** Since MD was explicitly identified in the pilot study, introduction bias may be a limitation. However, participants only confirmed MD-incidences and then described these incidences specifically (cfr. McCarthy & Deady, 2010).

Study 1 may be susceptible to common method bias.

**Implications:** Understanding the dynamic emotion processes underlying MD may help organizations develop interventions aimed at coping with MD. The outcomes of Study 1 may provide input for a context-independent assessment instrument for MD. This kind of instrument may be of practical use in the context of (psychosocial) risk analysis in health care organisations.

**Value:** This study might be the first using the componential emotion approach (component process model) to provide empirical evidence for the core features of MD. Furthermore, no study up to our

knowledge examined MD throughout different health care settings (in one study) and with this number of participants. Most scholars determining MD-evoking situations conducted semi-structured interviews with a limited number of participants. With Study 1, we aim to reach at least 200 health carers.

### **Nurses' perspectives and experiences on the concept of autonomy and professional autonomy**

*Seher Basaran (1), Leyla Dinç (1)*

*(1) Hacettepe University, Faculty of Nursing, Ankara, Turkey*

**Background:** Autonomy refers an individual's capacity for self-determination. It is a multidimensional concept that has psychological, sociological, political and philosophical aspects. From the point of moral philosophy is the capacity to deliberate and to give oneself the moral law without the injunctions of others. This conception is usually traced back to Immanuel Kant, and in bioethics, autonomy is considered as one of the four ethical principles. In the field of health care, respect for autonomy requires informed consent of a competent patient for any medical care or research. Professional autonomy concerns with the rights of practitioners and the professional group to determine the standards of behaviours for action or code of conducts without external control. Professional autonomy is one of the criteria for being a profession and it has a moral component.

**Purpose:** The purpose of this qualitative study was to explore nurses' perspectives and experiences on the concept of autonomy and professional autonomy.

**Method:** A purposive sampling of 21 nurses employed at general hospitals in Ankara participated in this study through semi-structured interviews. All interviews were audio-recorded, with the permission of interviewees and transcribed verbatim. Data was abstracted and analysed through an inductive approach by reading interview transcripts, identifying meaningful sections, extracting recurring themes via coding and categorizing main themes. Meaningful quotes from participants and field notes of observer were noted.

**Results:** Qualitative data revealed that most of the nurses define professional autonomy as 'independent decision making and implementation of nursing care practices based on professional knowledge, competency, responsibilities within the frame of laws, regulations and ethical principles without being dependent on others or any external control. Nurses stated that having professional autonomy would have several positive outcomes including the improvement of the quality of patient care, increase of professional status and power, the visibility of nursing and increase of nurses' satisfaction from the profession. In addition, they also expressed that professional autonomy has a moral dimension and conscientiously side, because unless based on scientific knowledge, clinical skills, competency and ethical code of conduct, professional autonomy might be harmful for patients.

**Conclusions:** Results indicate that professional autonomy is considered important for positive patient care outcomes and professionalism; however, professional autonomy must be based on competency and ethical attitudes.

## **Euthanasia embedded in palliative care: Responses to fundamental criticisms of the Flemish-Belgian model of Integral End-of-Life Care**

Jan Bernheim (1)

(1) *End-of-Life Care Research Group, Vrije Universiteit Brussel and Ghent University, Belgium.*

**BACKGROUND:** The Belgian model of ‘integral’ end-of-life care since 2002 consists of universal access to palliative care (PC) and legally regulated euthanasia. As a first worldwide, the Flemish professional PC organisation has in 2003 embedded euthanasia in its practice. However, some foreign critics, including –by majority vote– the European Association for Palliative Care, have declared the Flemish-Belgian-model concepts of ‘integral PC’ and ‘palliative futility’ to fundamentally contradict the very essence of PC.

**AIMS:** To analyse the various fundamental or essentialistic (epistemological, historical, conceptual, doctrinal and moral) arguments for the incompatibility of euthanasia and PC.

**RESULTS:** First, it is problematic that some critics dismiss empirical evidence as epistemologically irrelevant in what they regard as a normative ethical debate. The facts are that, though a few controversial cases of euthanasia and some transgressions of the law are on record, the bulk of the vast empirical evidence from the euthanasia-permissive Benelux countries shows that since the de-penalisation and regulation of euthanasia in 2002, carefulness [of decision making] at the end of life has improved and there have been no major adverse ‘slippery slope’ effects.

Next, rejecting euthanasia because its prevention was a founding principle of PC ignores historical developments.

Further, excluding euthanasia from PC departs from the PC tenet of patient-centeredness by prioritizing caregivers’ values over patients’ values.

Also objectionable is many critics’ canonical adherence to the WHO definition of PC which relies on *intention*, a poor criterion to judge actions.

Rejecting the Belgian model on the above *theoretical* grounds also has *practical* adverse consequences. These include the marginalisation of PC in euthanasia-permissive jurisdictions, the continuation of clandestine practices and problematic palliative sedation until death. Also, some patients will shun PC services that exclude euthanasia and will receive suboptimal PC treatment in non-specialised end-of-life care settings, where moreover euthanasia will tend not to be practiced in the PC spirit of ‘total’ care. Together, these two clinical consequences are likely to lower the overall quality of end-of-life care.

**CONCLUSION:** Major flaws of essentialistic arguments against the Belgian model include disregarding empirical evidence, canonically relying on disputable definitions, prioritising caregiver perspectives over those of patients, rejecting a plurality of respectable views on decision making at the end of life and the risk of undesirable practical consequences, both clinical and at the level of public health by marginalizing PC in euthanasia-permissive countries.

**“CONTRAST TO RESTRAINTS”: A project to contrast mechanical, pharmacological and environmental restraints in elderly care**

*Livia Bicego (1), Maila Mislej (2), Emanuela Fragiacomio (2), Giuseppe Sclipa (1), Pier Riccardo Bergamini (2), Claudio Pandullo (2), Francesco Antoni (3), Delli Quadri Nicola (2), Marco Tomietto (1)*

*(1) Azienda per l'Assistenza Sanitaria n.5 “Friuli Occidentale”, Italy*

*(2) Azienda Sanitaria Universitaria Integrata di Trieste, Italy*

*(3) Tribunale di Trieste, Italy*

Background: It is expected that by 2050 older people in Europe increase by 170%. According to this demographic evolution, even complexity and fragility in elderly care is increasing. In detail in Italy 18.7% of elderly people are frail and 2.7% are hosted in nursing homes. Institutionalization is a risk factor for mechanical, pharmacological and environmental restraints, especially for cognitive or functional impaired residents (Hofmann & Hahn, 2013). Physical restraints in Europe ranges from 6% to 85% (Kuronen et al. 2016) and it is associated with poor patients' outcomes such as risk for functional decline, lower cognitive performances, pressure ulcers, incontinence and mortality (Hofmann & Hahn, 2013).

It is ethically urgent to decrease restraints use in order to improve both patients' dignity and nursing care outcomes.

Aim: To improve organizational and professional projects in elderly care to decrease restraints use.

Materials and methods: A multi-based strategy was improved by involving institutions and stakeholders in the Trieste area. A committee was created in the Health Care Facility Service to promote conferences, training for health care professionals and to monitor restraints use in nursing care.

Results: At the beginning of the project, 32 nursing homes were involved in the survey and 811 residents were monitored. Sedative treatments were documented in 33% residents (269/811), while 42% were in bed with bed-edges. Physical restraints were delivered in 64/811 residents (7.9%).

Along years, a systematic approach in training for health professional and public opinion involvement has been performed. Surveillance has been acted. Restraint is neither a nursing or medical act and it has no evidence as a good practice. Along years, nursing homes involved became totally free of restraints use and some adverse outcomes significantly decreases, such has patients' falls and hip fractures.

Conclusion: Restraints has no ethical rationale in nursing care and they damage patients' dignity and outcomes. After a multi-intervention strategy, nursing homes in the Health Care Service are now completely free of restraints and nursing outcomes significantly improved. Moreover, nursing homes are now restraints-free and ethically driven.

Further perspectives: In the Pordenone and the whole Regional area (Friuli-Venezia-Giulia) new data collection is starting in nursing homes and medical wards, data about restraints use prevalence and adverse events are monitored, pilot study results will be ready in June 2016.



An international network has been created in defining a model to avoid restraints use in health care facilities, at the moment Spain and Brazil joint the network and a committee is working to enhance practices to forbid restraints under the professional, legal and ethical point of view.

In Italy bioethics committees has been involved and specific teams are working to avoid restraints in hospital settings as well. In one pilot hospital restraints use was forbid and preliminary results demonstrates it is possible to reach this goal. Volunteer teams has been created to improve surveillance and nursing care for high risk patients without using restraints.

### **Ethical issues and dilemmas in voluntary work with older people in Sweden: A pilot study**

*Kerstin Blomqvist (1), Malin Sundström (1)(2) Anna-Karin Edberg (1)*

*(1) Kristianstad University, Kristianstad, Sweden*

*(2) Malmö University, Sweden*

Background: Within the LONE-study "Existential loneliness - a challenge in health care to the elderly frail people", we have conducted individual interviews with older people and their families and focus groups with health care staff to explore the meaning of, and approach to, existential loneliness. An additional group that is becoming increasingly important, but often work in the shade, is volunteers who visit older persons who suffer from loneliness and lacks someone to talk to about meaningful aspects of life and existential issues. The group of volunteers is heterogeneous and includes both young and older people with different backgrounds and experiences. Recruitment is usually done through various organizations such as Relatives' associations, the Swedish Church, the Red Cross or the municipality. From an international perspective, volunteers often play a significant role in health care. One reason why volunteering is not so developed in Sweden is that health and social care is financed by taxes and thus considered to be a societal responsibility. More recently, voluntary work has become increasingly accepted as an important supplement to social care of older people in Sweden. We have however limited knowledge about the significance and the role of volunteers in care for older people, in particular from the volunteers' own perspective.

Aim: The study aims to examine the role of volunteers in the care of older persons with specific focus on aspects related to the motive to become a volunteer, what difficult situations that can arise, what support the volunteers need and how this support should be organized.

Method: As a first step, a pilot study based on focus-group interviews with two groups of volunteers were performed and content analyzed to find issues to go ahead with and explore more in-depth.

Findings: The pilot study shows that volunteering, at best, can play an important role both for the older persons and for the volunteers. Thus voluntary work could be health promoting and help reducing the loneliness of both parties. However, findings also show that volunteers sometimes end up in ethically difficult situations but that they rarely have anyone to discuss these issues with.

Conclusions: The pilot study indicate that the volunteers need, and desire, opportunity to meet together and discuss ethical issues and dilemmas as well as benefits of being a volunteer. Meetings for volunteers could be a way to support them in their role but how and by whom such meetings should be chaired and how older persons' privacy could be protected need to be explored. Thus, further

studies are needed to investigate how meetings should be organized in order to be part of a sustainable volunteer organization. There is also a need to further explore volunteering as a health promoting activity not only for older persons but for volunteers as well. One question that need to be asked is if a “matching” of the volunteer and the older person is a way to maximize a deep and health promoting relationship and how this could be performed.

### **Abusing ethics: Recurrent uses of ethical fallacies among nurses**

Benjamín Olivares Bøgeskov (1)

*(1) Nursing Education University College UCC, Denmark*

This paper presents the result from our research on how nurse managers use and occasionally misuse inconclusive ethical arguments to engage their personnel in current reforms.

The Danish health care system has undergone a series of reforms inspired by New Public Management theories, which have promised better services for lower costs. Despite the positive intention, such reforms have not always been received as such by front line nurses, who often see an opposition between these processes with their focus on efficiency and the fundamental values of nursing. In this climate, nurse managers responsible for implementing the reforms, struggle to find ways to reconcile the conflicting interest of nurses and reforms, in order to engage their personnel in this process of change. Based on observation, individual and focus group interviews we collected and analyzed the arguments given by managers, paying special attention to the way in which ethical arguments are used in relation to engagement. Our research shows that ethical arguments are extremely common, and they are used either to elicit engagement, or to demand engagement considering the result of a duty. However, most interestingly it was possible for us to find recurrence of fallacious arguments of different kinds.

Based on these findings, I will argue that the use of fallacious arguments in order to generate engagement is in reality an abusive use of ethics, which raises important questions. I argue that depending on the degree of awareness of the use of a fallacy, eliciting engagement with fallacious arguments can be in itself and unethical action. I will also like to point out the potential conflict that can arise from abusive argumentation methods. Finally, I will focus on how paying attention to the structure of arguments used in reform processes can be an important tool for promoting dialogue in situations, which are otherwise often perceived as power struggles.

### **Discovering and avoiding self-contradiction: Teaching the principles of ethical dialogue among nursing students**

Benjamín Olivares Bøgeskov (1)

*(1) Nursing Education University College UCC, Denmark*

This paper presents an innovative method to teach ethics, which has so far been implemented amongst Danish students. The method focuses on developing skills to conduct a methodical, ethical dialogue by teaching students to become aware of self-contradictions and learning to avoid them.

This method was created as a response to a recurring disappointment relating to the common way of teaching ethics in Danish nursing schools, in which students are introduced to ethical theories and asked to use them to reflect on concrete ethical cases. In these courses, quite commonly students were able to understand the theory and see the consequences of such theories in concrete cases, but would not use any of these theories to justify their own ethical decisions in other contexts. In other words, courses were failing to provide the students with theoretical tools that they could apply outside the classroom. Therefore, this method focuses not so much on teaching what other people think, but rather starts by finding out what the students think, and to which degree they contradict themselves. In addition the method focuses on how students argue for their positions when entering an ethical dialogue.

The method focuses on two aspects –first developing critical self-reflection and secondly developing skills to conduct an ethical dialogue. The first aspect is addressed by finding out what the students think, do they contradict themselves and how to avoid self-contradictions. This is done by using a questionnaire with 13 ethical questions, which are designed so it is easy to contradict one self. The questionnaire includes a reflection table, which allows students to discover their possible contradictions. Then students learn to establish morally relevant differences, as a tool to avoid possible contradictions.

The second aspect (learning the skills to conduct an ethical dialogue) builds on the previous ability to identify contradictions. This is done by focusing in 4 basic rules that introduce the basic principles of a dialectical dialogue. These rules allow them to avoid fundamental mistakes which otherwise hinder an ethical dialogue.

One of the advantages of this method is that it demands little knowledge of ethical theories, which has allow us to introduce it amongst clinical nurses, who have use it to qualify the ethical reflections among the students doing internships with them.

Furthermore, given that the method uses a questionnaire it has been useful to gather data on student's reflection level, which shows potential to evaluate their development, and to conduct further research.

In this paper I intend to present and explain the method, present its value, show some of its results, but also show the aspects which demand further development.

### **Existential loneliness among frail older people**

*Ingrid Bolmsjö (1), Anna-Karin Edberg (2), Kerstin Blomqvist (2), Marina Sjöberg (1)(2), Helena Larsson (1)(2), Malin Sundström (1)(2), Ingela Beck (2)(3), Margaretha Rämgård (1), Birgit Rasmusson (3)*

*(1) Malmö University, Malmö, Sweden*

*(2) Kristianstad University, Sweden*

*(3) Lund University, Sweden*

Background: Loneliness is one of the most central existential issues in human life. All of us during our life track will experience different kinds of loneliness. Social loneliness is the most studied aspect which deals with no or poor relations. One aspect which is less studied is existential loneliness. The phenomenon is complex and lacks consensus regarding the definition and meaning. However, the

phenomenon is discussed in the literature and according to the amount of articles we can assume that existential loneliness exists. When growing old losses of different kinds are inevitably and as a consequence existential loneliness seems to appear. For health care personnel it is not merely medical problems that should be in focus but also existential needs and thus, it is from an ethical point of view reasonable that health care personnel should be able to meet and handle existential loneliness. We know that caring for people at the end of life is existentially challenging, as dying and death are constantly present, especially in the care of older people. As all frail older people are by definition in the last phase of life, we can assume that they experience existential loneliness to some degree. However, existential loneliness is a multifaceted phenomenon that needs to be further explored.

**Aim:** The aim of the study was to explore existential loneliness from the perspective of frail older people, their next of kin's and health care staff, working in different care contexts.

**Methods:** The study comprised three sub-studies with different samples and qualitative approaches. Individual interviews were performed with (I) 23 persons aged 76-101 years, (II) their relatives (n=19) aged 49-86 years, and (III) 11 focus group interviews including, in all 61 health care staff working in different care contexts. Data from the individual interviews were analysed using (I) a phenomenological-hermeneutic approach and (II) a conventional content analysis, while the focus group interviews (III) were analysed using an inductive-deductive approach.

**Results:** The results from the three sub-studies revealed that older people, the next of kin's and the staff gave similar and complementary images, which concerned the importance of body and space, being able to share significant aspects of life, and purpose and meaning. It was also evident that existential loneliness was not reduced by having people around – it could rather reinforce the experience. From the perspective of staff, the ability to encounter older people's existential loneliness was influenced by different barriers related to bodily, social, personal and spiritual aspects.

**Conclusion:** The results showed that existential loneliness meant being disconnected from life, or being in a process of disconnection from family and friends, places and things of importance. From the perspective of staff, several ethical aspects involved in how they encounter existential loneliness, such as having the courage to be exposed to, and encounter, others' suffering and existential pain. The development of supportive means for health care staff need to include support to the staff themselves, but also a variety of different tools to facilitate verbal as well as non-verbal communication.

### **E-book alternative communication board for injured patients in intensive therapy unit**

*Maria Helena **Borgato** (1), Paula Mayra Napolitano Ramos (2), Luciana Esgalha Carnier Bazoni (2), Cassiana Mendes Bertoncetto Fontes(1)*

*(1) University Estadual Paulista Julio de Mesquita Filho -SP-Brazil*

*(2) Residency Program in Adult and Elderly Health at Unesp Botucatu Medical School, Brazil*

Intensive Care Units (ICUs) are characterized by being full of high technical scientific complexity, their patients are submitted to various procedures and interventions, many of them compromising their ability to communicate. Communication is an essential element in human life and quality of life, especially in times of such fragility as in the case of an ICU hospital stay. It contributes as much to the medical and nursing staff to intervene physically as to the psychology team to intervene in the

emotional aspects related or not to hospitalization. In this way, it is necessary to create instruments to enable the alternative communication of these people, since the normal way of communication may be compromised. Alternative communication is understood as the set of methods and techniques that enable communication, complementing or replacing compromised or absent oral language. In this study, a low-tech resource was used to enable the communication of patients admitted to the ICUs. The main objective is to identify the feelings and sensations of these patients, to perform care and psychological care, to intervene in physical and social aspects that may contribute to their well-being and enable greater interaction with all staff and families. The board is composed of corresponding figures and words, thus facilitating the stimulus presented to the patient. The figures were separated into categories based on Wanda Horta's Theory of Human Needs. To facilitate the presentation and understanding of the interlocutor, in which the Psychobiological, Psychosocial and Psycho-spiritual needs are proposed. To facilitate the handling of the material, we chose to name the categories as follows: "sensations", "body parts", "risks and / or interventions", "needs and wants" and "objects". The figures that will be presented to the patient are chosen according to the demand of the same or the unit team. For example, when he wants to identify what the patient is feeling physically, he is shown the board corresponding to psychobiological needs such as "pain, cold" ... Then he is asked to point to the drawing that best translates his sensation. If the patient is unable to point, the interlocutor does so and asks the patient to react in some way when the appropriate figure is present. This reaction can be done by flashing, shaking hands, etc. It is hoped that this material will contribute to the care of ICU patients with communication difficulties, thus enabling a better stay in the unit for the same, facilitation in the team work and interaction with the family.

### **Perception of female adolescents in relation to HIV vulnerabilities**

*Maria Helena **Borgato** (1), Anataly Miranda (1), Cassiana Mendes Bertencello Fontes (1)*

*(1) University Estadual Paulista Julio de Mesquita Filho –SP, Brazil*

Infection by Human Immunodeficiency Virus (HIV) remains of great relevance to public health in Brazil, and in the young population the rate of infection tends to increase. Considering that sexual practices in adolescence are occurring earlier and earlier, sexual education and education to prevent HIV vulnerabilities should become priorities. The HIV epidemic in Brazil is concentrated in populations under situations of greater vulnerability and can be divided into three basic analytical levels: individual, social and programmatic, which are dynamically and interdependently related. This is a qualitative research. A questionnaire to identify the participants and a semi-structured interview during previously scheduled Nursing visits, were applied. The data collection site was the Basic Health Unit CECAP, in the City of Botucatu, from July to October, 2015. There were 25 interviews with adolescents between 15 and 18 years of age from the first to the third grade of High School. Results: The main vulnerabilities found in each level, were: Individual vulnerability; Adolescents not identifying themselves at risk; Social stigma of promiscuous life and the risks to HIV; Knowledge about sexual behavior at risk; False idea of stable relationship as immunity to HIV and other STDs; First sexual relationship and the ideal partner; Search for the ideal beauty pattern; Social vulnerability; Gap and lack of openness and dialogue between parents and their sons and daughters; Prostitution as an early exposure factor to sexual behaviour; Economy and access to information; Religion as a determinant on sexual behaviour of the adolescent; Meaning of the sexual intercourse; Programmatic Vulnerability;

Lack of preventive actions in Brazil; Social stigma about sexuality and STDs; School as the main educational agent; Untrained professionals. Conclusion: After more than 30 years of HIV / AIDS discovery, there is still lack of information and preventive actions from public authorities and adolescents have been exposed to sexuality earlier and earlier, forcing them to make up the personality and identity, and consequently willing to experiment something which may often be risky. A new outlook becomes necessary for young people education in schools, new educational programs of the Ministry of Health aimed at specific age groups and trained professionals. Therefore, this study shows that there is still social stigma, prejudice, fear, shame and mainly lack of information from adolescents and the population about HIV / AIDS.

### **Identifying the triggers of ethical conflict in the initiation of advance care planning for persons living with dementia in nursing homes**

*Kevin **Brazil** (1), David Scott (1), Gillian Carter (1)*

*(1) Queen's University Belfast, UK*

Family and staff carers are often asked to make decisions or participate in decision making about end-of-life care and treatment. Some of these decisions may impact on the patient's comfort, well-being and dignity, and some may affect the duration or quality of the patient's remaining life. If carers do not fully understand the process or consequences of their decisions they may wrongly believe that they have contributed to the patient's death or suffering. Advance Care Planning (ACP) has been defined as a process of discussion between a patient, their health care providers, and those close to them, about future care in the event that the patient may lose capacity to make decisions for themselves, as their illness progresses. As such, it has become viewed as a means of navigating the uncertainties at the end of life by identifying and supporting patients' needs and preferences for care. The purpose of this qualitative inquiry was to identify the factors that trigger ethical conflict and subsequent distress for both family and staff carers associated with the initiation of ACP discussions regarding end-of-life issues in dementia care. Identifying the triggers for ethical conflict represents the first step in addressing this issue.

Research design and procedure: A mixed methods paired cluster randomised control trial of an ACP family focussed intervention was conducted in 24 nursing homes located in the United Kingdom. Nursing home managers and family carers who participated in the trial were invited to participate in a semi-structured individual interview.

Interviews with nursing home managers focused on how the ACP intervention helped or hindered care in their facility. Family carer interviews focussed on the experiences of making decisions on goals of care for a family member living with dementia. All interviews were conducted in the nursing home in a private room. Sample size was determined through information saturation.

Analysis of data: Semi-structured interviews were transcribed verbatim and thematic analysis was completed with the goal to identify the triggers for ethical conflict surrounding the initiation of ACP from both staff and family carer perspective. To ensure validity and rigor, transcripts were independently analysed by team members and agreement on themes reached through discussion.

Results: 10 Nursing home managers and 14 family carers were recruited from 10 nursing homes. Analyses of the family carer interviews revealed five issues that triggered ethical conflict associated with the initiation of ACP: (a) guilt and burden, (b) the nature of dementia and timing of ACP discussions, (c) cultural norms, (d) communication within family members and staff, and (e) complexity of ACP information. Interviews with nursing home managers identified three issues that triggered ethical conflict: (a) communication with family carers, (b) the nature of dementia and timing of ACP discussions, (c) staffing related issues.

Conclusions: Identifying the triggers for ethical conflict provides guidance on the development of strategies clarifying how ACP should be integrated in the processes of care present in nursing homes.

### **The experience of moral distress for Australian aged care workers: Opportunities for change**

*Adam Burston (1), Anthony Tuckett (1), Robert Eley (2), Deborah Parker (3)*

*(1) The University of Queensland, Australian Catholic University, Brisbane, Australia*

*(2) The University of Queensland, Princes Alexandra Hospital, Australia*

*(3) The University of Technology, The University of Queensland, Australia*

A healthy and sustainable health workforce is essential for supporting the older person to age well within residential and community care environments. It is widely acknowledged that with an ageing population in Australia demand for aged care services will increase. Concurrently an ageing workforce is challenging the capacity to meet this service need. Job satisfaction and worker retention are negatively impacted by moral distress; and whilst moral distress has been investigated across a range of clinical contexts and countries, little research exploring moral distress in the Australian or the aged care contexts is evident.

This mixed-methods study was undertaken in two phases, and explored the effect of moral distress on Australian aged care workers in residential and community aged care. Participants consisted of Registered Nurses, Enrolled Nurses, and Personal Care Workers (Assistants in Nursing) from Queensland and Victoria, Australia. Phase 1 involved the amendment and testing of an instrument to measure moral distress, while Phase 2 involved the collection of qualitative data using both written scenarios as stimuli and individual interviews with participants.

In Phase 1 the amendment and validation of the Moral Distress Scale – Revised was undertaken (n=106). The objective was to validate an instrument for use within the aged care workforce. The amended instrument demonstrated strong reliability (Cronbach's alpha 0.94). Mean item scores identified moral distress occurring with low frequency but moderate intensity within this population. Exploratory factor analysis identified three factors: Quality of Care, Capacity of Team and Professional Practice.

In Phase 2 a thematic analysis was applied to both interview (n=9) and written scenario (n=16) data. The objective was to further illuminate the experience of moral distress for this population to support targeted interventions. Workers described a range of effects including sadness, unhappiness, and extreme frustration; related to the impact on themselves, other workers, and the older person in their care.

Workers in this population also identified clear opportunities to act as an advocate in morally distressing situations. Participants expressed a desire to lead ethical practice in a bid to reduce the occurrence and alleviate the effects of moral distress. Individually, working to change practice delivery by either 'doing' or 'not doing' was identified. Additionally engaging in advocacy through communication with others within and without the healthcare team was seen as critical to resolution.

Australian aged care workers do experience moral distress, and this distress causes a range of detrimental effects. Worker engagement with solutions was clearly identified as a key factor in reducing the occurrence and the intensity of the experience.

### **The (f)law on euthanasia: Mental suffering and euthanasia: clinical-theoretical nuances**

Marc Calmeyn (1)

(1) (1) *Psychiatric Hospital OLV Bruges; Private Practice 'Lelieveld' Loppem Zedelgem, Belgium*

The (Belgian) law for euthanasia and its implementation are examined in a constructive yet critical manner in this presentation. Both clinical and theoretical nuances are introduced throughout accurate exploring and getting acquainted with – the etymology of diagnosis - what euthanasia covers. Going beyond ideological polemics is one of the aims as well as adding a fundamental contribution to this social – ethical debate.

In the first part of the presentation comments on the various legal criteria for euthanasia are given. The altered mode of thought concerning mental health care is dealt with as well. Cost efficiency and result are emphasized, the motto is 'short yet powerful'. Nevertheless, a high price is paid for this approach by man as a subject.

In the first conclusion it's said that the specific nature of the psychopathology can't find its reproduction in the somatic-medical legislation for euthanasia and its implementation. The anthropological difference is neglected and the individual's autonomy is rather restricted, this opposed to the popular vision. Furthermore, subjective suffering doesn't hold the future. Elucidation of these concepts compels reconsidering ethical choices. After all, as long as there is hope, there is life?

In the second part of the presentation the legislation for euthanasia and its implementation are 'diagnosed' in a constructive yet critical way. Starting from psychosocial differentiations, a refinement is possible of the process of getting acquainted with– which is the etymology of diagnosis – what euthanasia is all about. This second part mainly deals with what is *not* covered by the law. The implicit messages in the explicit message 'I want to die', the therapeutic relation, the position of power by the doctor and some social tendencies are dealt with. Furthermore some arguments in favour of euthanasia are commented on.

Critical reflection leads to the consideration for euthanasia to be a symptom (relief) rather than a solution; a symptom resulting from the denial of the particularity of psycho(patho)logy. The therapeutic relation, motor of change, is essentially different in psychiatric illness. The doctor - with his vision, experience, anxiety, shortcomings ... - as a person is a lot more implied in psychosocial care than in somatic health care.

Following, euthanasia is accepted as symptomatic for our current western society with its ideal of the young, healthy, performing citizen. Suffering, illness, ageing and death are no part of this. Problematic is above all that there is no place for the suffering, ill, older and dying people either.



## **Transformational leadership and the ethics of caring where danger lurks**

Donna Casey (1)

(1) *Christiana Care Health System, Newark, USA*

Practice environments are increasingly dangerous from workplace violence, natural disasters and emerging infectious diseases. Ethical challenges confront nurses daily from issues such as impaired practice, use of social media, advance care planning and end of life. Nurse leaders' efficacy is impacted by shrinking resources combined with requirements to 'do more with less'. The imperative to improve quality and patient experience can feel overwhelming.

Transformational leadership is the optimal style to inspire nurses concerned about their own safety, to transcend self-interest and empower action enabling optimal contribution. The emotional component of leadership, combined with inspirational motivation, intellectual stimulation and individualized consideration equips the nurse leader to successfully confront any crisis. This interactive session demonstrates how to use the tenants of transformational leadership with the American Nurses Association (ANA) Code of Ethics as nursing's non-negotiable promise to society, as well as the ANA newly revised position statement on risk & responsibility to touch the heart and soul of nurses. The Code steadfastly supports nurses across all settings and in all roles addressing the wide variety of relationships nurses encounter in the profession and iterates the fundamental values and commitments of the nursing profession. Specific provisions are highlighted as they enlighten the moral obligation of the profession to care, while simultaneously require the nurse to care for self. This session is significant for participants because evidence demonstrates that violence in healthcare settings, natural disasters and emerging infectious diseases are on the rise. Society will rely on the most trusted profession for our presence and expertise. Nurse leaders need to be prepared with knowledge and skill to navigate through the unknown with confidence and a solid team of expert nurses ready to take action.

Ethical nursing leadership is needed to motivate and inspire nurse to achieve quality outcomes. This presentation will address these ethical issues faced by nurses and nurse leaders, and the moral imperative of organizations to provide support.

## **What counts as consent? Sexuality and ethical deliberation in aged care**

Catherine Cook (1), *Mark Henrickson* (2) *Vanessa Schouten* (3)

(1) *Massey University School of Nursing Auckland, New Zealand*

(2) *Massey University School of Social Work, New Zealand*

(3) *Massey University School of Humanities, New Zealand*

Aim: The aim of this pilot project was to interrogate the notion of consent in the domain of sexuality and intimacy in residential aged care (RAC). Using insights gained from residents, caregivers and residents' families, we addressed the questions: What kinds of ethical decisions are being made about expressions of sexuality in RAC? How do staff, family members and residents rationalise those

decisions? Are there more general implications for our understanding of the ethics of sexuality and consent?

**Background:** Discourses of ageing readily construct people in residential aged care as post-sexual, vulnerable and at risk of sexual exploitation, and therefore expressions of intimacy and sexuality may be responded to as deviant and inherently risky. Staff may manage decision-making tacitly, without recourse to policies and education. The current consensus in the theoretical literature on the ethics of sex and intimacy is that consent is of fundamental importance. The emerging concept of sexual citizenship is used to argue for the rights of people living with dementia to enfranchisement, belonging, equity and justice; therefore institutions' risk-aversion toward sexual expression may be understood as a violation of these rights.

**Design:** The proof-of-concept study utilised a discursive methodology, identifying discourses that shape diverse meanings of intimacy, sexuality, ageing and consent. Data analysis involved thematic analysis.

**Methods:** Semi-structured interviews were conducted with four participants in 2015: a registered nurse; a healthcare assistant; a resident; and the daughter of a resident.

**Results:** Four themes were identified in the data analysis: mediated intimate relationships and everyday ethics in RAC; self-referential morality; knowing the person then and now; and juggling ethical priorities. Data indicated that participants used their personal 'moral compass' to inform their decision-making, without any related policies and applied ethics and communication education. As a result, staff described situations in which they experienced moral uncertainty and moral distress. Staff indicated that at times there were tensions in terms of the role of proxy decision-makers, as there were situations in which staff believed they were far more aware of residents' current wishes and cognitive capabilities than family members. Proxy decision makers (both carers and family members) drew on tacit moral understandings which conflated wellbeing with consent in order to make complex decisions about intimacy and sexuality.

**Conclusions:** Staff, families and residents routinely address intimacy and sexuality in aged care. Where there are unattainable cognitive pre-conditions, the emphasis on curtailing risk may result in excessive paternalism, breaching resident rights and diminishing quality of life. An assessment of wellbeing is an essential component of ethical decision-making.

## **Empathy and the intentional provision of care**

### ***Trees Coucke (1)***

*(1) University for Humanistic Studies, Utrecht, The Netherlands*

**Aim:** The purpose of the review is to examine whether the concept of empathy and other related concepts lead towards an intentional provision of care?

**Introduction:** Between Rogers and now a lot of researchers have written about empathy. Morse and Kristjansdottir have analysed the concept in the psychological and nursing literature but determine that the concept is incomplete. According to Rizzolatti empathy is a category of stimuli that appear to be of great importance for people and primates and are formed by action or by observing another. In

order to survive, people must understand the actions of others. Peplau and Asada describe 'emotional contagion' as an evolutionary forerunner, which enables animals to share emotions without understanding what the emotion has provoked in the other. Emotional contagion occurs in people, whereby people feel the emotions of the other as their own, without necessarily realising that they come from the other.

Later on researchers add components and conditions as cognition, emotion, imagination, reflection and mirror neurons to make the concept of empathy more complete and more descriptive. Certain forms of empathy that were initially seen as purely human also appear in primates, elephants and dolphins.

Discussion: There are a lot of challenges for empathy: system pressure, time pressure, the management, the 'struggle' of the care-provider (CP) to be able to imagine the life experiences of the care-receiver (CR), the physical reaction of disgust, turning away from pain and suffering, self-protection against the suffering, powerlessness. Finally, it is not an imaginary result that emotional connectedness fades due to the impossibility of changing the situation of the other person.

Related concepts were examined (compathy, pity, sympathy, compassion) and it appears that these concepts partially overlap and are often used interchangeably. Compassion has gained importance and is seen as a necessary part of nursing care. Ultimately, good care needs something from all the concepts but compathy and compassion indicate some intention to provide good care. Empathy is, not enough to build up an attentive and caring relationship, nor does it trigger action, at the most an intention. Related concepts help to supplement the care relationship and to make the dialogue possible, in order to get to know the challenges and tasks of the CR, but how do we get to know these?

Conclusion: Compassion, empathy and sympathy are necessary ingredients in order to get a view of who the CR is, what his needs, challenges and longings are and, in dialogue, to come to a useful plan of care. Empathy alone is not enough. In the search for a direct action motivation, inherently present in the concepts, it appears that some of the concepts provide an intention to care but whether these concepts yield a strong motivation to act and deliver, in an effective way, good care is not proven. The question remains: what exactly triggers action and how exactly can this intention be strengthened? Research into the application of imagination and exposure in simulated situations is needed.

### **Challenges and opportunities in end of life care: Experience of facilitating the journey of change programme in the Republic of Ireland**

Una Cronin (1)

(1) *University College Cork, Cork, Ireland*

The aim of this presentation is to describe and consider the value and impact of an innovative end of life care programme for older people living in residential care. A Journey of Change (JOC) was implemented across the Republic of Ireland from January 2015-December 2016. In my role as a Development Officer (DO), I was involved in developing and implementing the JOC programme. The experience was both inspiring and challenging. My presentation will include discussion on the positive aspects and the difficulties that arose with the programme.

The aim of JOC was to enhance respect for individual autonomy at end of life by developing a culture of person centred care in nursing homes and community hospitals (residential care centres (RCCs)). The programme, designed by the Irish Hospice Foundation, took an innovative approach, with 3 different categories of membership offered. DOs supported staff to expand their competence in end of life care through a process of reflection on care practices, recognition of good practice and acknowledgement of areas for development.

A key opportunity of the programme was the formation of a multi-disciplinary Compassionate End of Life (CEOL) group within the RCC whose major function was to complete a comprehensive care review after the death of each resident. As a consequence, many positive changes in practice ensued. For example, end of life privacy and dignity was enhanced by developing/upgrading a specific room for use at end of life.

I also encountered challenges and limitations. One of the challenges was obtaining protected time for CEOL reviews in some RCCs. A potential limitation was that it may have been only RCCs who were already versed in ethical principles and were interested in practice development joined the programme.

Feedback from RCCs who completed JOC has been largely positive and programme membership has contributed to enhanced autonomy for residents at end of life. More detail of the facilitation experience and programme evaluation will be presented at the conference.

JOC team; Marie Lynch (Head of Healthcare Programmes), Anna de Siun (National Development Co-ordinator, Residential Care Centres), Regional Development Officers: Hilary Smyth, Aoife O'Neill, Mary Lovegrove, Jacinta Kelly, Thelma Pentony, Joanne Brennan and Una Cronin.

### **'Care Ethics Lab': Evaluation results**

***Bart Cusveller (1), Annemiek Schep-Akkerman (1)***

*(1) Hogeschool Viaa, Zwolle, The Netherlands*

Moral formation of nurses is considered important by most but effective strategies for ethics education for nurses are contested by many. A recent development in ethics education for nurses is the implementation of simulation sessions, in which student and professionals are exposed to aspects of awareness and attitudes like empathy and flexibility. Examples are to be found in Belgium (sTimul), England (Sussex) and The Netherlands (Zorgethisch Lab). Still, not much by way of empirical data is available on the results of such sessions.

In this paper I would like to present the results from our evaluation of the first year that the 'Care Ethics Lab' in Zwolle, The Netherlands, was operational. Participants in the labs filled out evaluation forms directly after participation and again after some weeks. While also still in the process of developing appropriate tools to measure the outcomes of simulations sessions, the preliminary results show that participation in simulation is a powerful learning instrument, but also that further fine-tuning of the sessions and evaluation is necessary.

### **Development of the Ethics Meetings in Nursing Competency Scale (EMIINCS)**

***Bart Cusveller (1), Annemiek Schep-Akkerman (1)***

*(1) Hogeschool Viaa, Zwolle, The Netherlands*

In many countries, nurses are expected to participate in moral deliberation and decision-making. In many cases this takes place in more or less organized or formalized forms, like multi and mono-disciplinary consultations, ethics committees, moral case deliberation, or other kinds of ethics meetings. To participate in such meetings competently, nurses need certain knowledge, skills and attitudes. The literature describes which competencies nurses find important for participation in such ethics meetings. To select and equip nurses for participation in organized forms of moral deliberation and decision-making, however, it is also necessary to know if nurses and nursing students do indeed possess or develop the required competencies. For this purpose, a questionnaire has been developed and in this presentation I would like to present and discuss the results of the first tests with this tool.

### **Autonomy in home-dwelling elderly in Iran: A phenomenological study**

***Ali Darvishpoor Kakhki (1), Zhilla Abedsaeedi (1), Ali Delavar (2), Patricia Davidson (3)***

*(1) Shahid Beheshti University of Medical Sciences, Tehran, Iran*

*(2) Allameh Tabataba'i University, Iran*

*(3) Johns Hopkins University, USA*

**Introduction:** The elderly are the fastest growing segment of the population globally. This is also the case in developing countries such as Iran. Maintaining autonomy and independence is a key goal for active ageing. This study was conducted to understand and obtain a deeper insight into the lived experiences of autonomy among older people.

**Method:** A qualitative research design based on van Manen's phenomenological methodology was conducted. Purposive sampling was undertaken and in-depth interviews were used to obtain data from 15 older people. Interviews were audio taped and transcribed verbatim for qualitative analysis.

**Results:** Autonomy was the overarching premise emerging from the data illustrated by four themes. These themes were: being the manager of self, not being a burden on others, maintaining financial independence and being able to live in my own house. Being manager of self included sub themes of maintaining an independent identity, undertaking decision making, being stubborn and maintaining their authority. Not being burden a burden on others included sub themes of self-care ability, functional autonomy and maintaining a sense of worth in the family and community. Financial independence included sub themes of experiencing inflation and decline of wealth, fear of financial dependency, the need of financial trustworthiness when delegating authority and the relationship between financial power and health status. Being able to live in my own house included sub themes of the separate life of children and their families, fear of living in a nursing home and maintaining dignity and independence.

**Conclusions:** These data illustrate the desire of Iranian elderly to maintain autonomy and independence. These findings will assist nurses obtain a deeper understanding of the older person's experience and to develop strategies to promote autonomy and independence.

### **Patients' privacy and related factors in cardiac care units in Tehran hospitals**

*Ali Darvishpoor Kakhki (1), Hamideh Sarkhil (1), Ziba Farahani (1)*

*(1) Shahid Beheshti University of Medical Sciences, Tehran, Iran*

**Introduction:** Increasing rate of cardiovascular diseases in developing countries such as Iran lead to increase hospitalization in Cardiac Care Units (CCU). The curing and caring procedures in this unit compromise the patients' privacy. This study was conducted to describe factors related to patients' privacy in CCU of Tehran Educational Hospitals.

**Methods:** This descriptive study was conducted on 300 patients in six educational hospitals located in different regions of Tehran. Self-reports of socio-demographics, disease rates, and their experience of privacy were collected via questionnaires. Data were analyzed with SPSS software.

**Findings:** 50.7% of patients were female and 74.3% married with a mean age of 61.5 ( $\pm 11.95$ ). 36.7% had elementary education and 44% were housewives. 59.7% had no hospitalization in the last year and 38.7% had no hospitalization experience in CCU. 64.7% stayed less than five days in CCU. Most of patients gave a low score on respecting their privacy (59.6%). The lowest score related psychological privacy. There were significant correlations between age, sex, marital status, educational level, job status, previous hospitalization, annual physician referrals, duration of staying in CCU, occupied bed rate, and privacy dimensions.

**Conclusion:** Results revealed a need to improve patients' privacy in CCU. Considering related factors and tailored and targeted strategies are inevitable to improve patients' privacy in CCU.

### **Development, implementation and evaluation of an integrative learning path for deep level learning of person-centered organization and coordination of care**

*Leentje De Wachter (1)(2), Sabine Monsecour (1)*

*(1) University College Leuven-Limburg, Belgium*

*(2) sTimul Care-Ethics Lab, Lubbeek, Belgium*

**Background:** High-quality care is person-centered care (PCC). PCC is not just about *what* a caregiver does for the patient or client, but also about *how* he does it. Interpersonal skills and a specific kind of attention based on ethical commitment are essential in getting to know the needs and wishes of the patient/client and to align the organization of care with those needs. Today's healthcare practice is often strongly focused on task-oriented nursing. In nursing education, theory and practice are often offered too little integrated. There is a need to coach students and support them in their learning process so that they can practice person-centered care.

This OOF-project POZ offers an answer to the lack of an efficient and manageable trajectory to learn person-centered organization and coordination of care. A blended learning path for integrated and deep level learning has been developed.

Methods: The POZ-learning environment is designed from Task-Based Learning (DBL) that uses the principles of blended learning in which active and motivated learning is encouraged. The educational model 4C / ID of Jeroen Merriënboer is inspiring. Through backward design, a learning environment is created that consists of two complementary parts: on-campus (classroom and teacher) and off-campus (online and workplace learning). As the learning path progresses, the share of off-campus increases. The on-campus part reduces but does not disappear because on-campus learning remains necessary given the importance of relational engagement in the learning process.

Findings: The implementation of the POZ-learning pathway in nursing education requires a radical rethinking of the role of lecturer and the organization of the educational program. For this reason it is in the first place necessary to invest in the training of lecturers. A training program, a frame work and a detailed learning path (POZ-pad 1) are developed to inspire and support lectures in creating their own course based on the principles of integrative and deep level learning.

### **How to realize dignified care for female Islamic patients? A qualitative study of intercultural care experiences in maternity care units in Flanders, Belgium**

*Liesbet Degrie (1), Chris Gastmans (1,2), Bernadette Dierckx de Casterlé (3), Yvonne Denier (1,2)*

*(1) Centre for Biomedical Ethics and Law, University of Leuven, Belgium*

*(2) Zorgnet-Icuro, Care Network Flanders, Belgium*

*(3) Academic Centre for Nursing and Midwifery, University of Leuven, Belgium*

Although globalization, migration and multiculturalism raise many debates within contemporary societies, the question on how to realize dignified care in this intercultural reality is still underexplored. According to the WHO, healthcare services should ensure culturally appropriate care (WHO, 2010). Nevertheless, international research still shows inequalities, barriers in access and a lower quality of care for ethnic minority patients. Many intercultural challenges are still visible in daily care practices. Especially in the hospital setting, when care is acute and inevitable, the realization of dignified care is compromised by intercultural factors such as, language and cultural barriers, differences in understanding health and treatment, negative attitudes, lower health literacy in ethnic minority groups and scarcity in hospital resources. Against this background, caregivers and patients have to try to find an ethically founded dignified answer to a situation of human vulnerability.

For the time being, the intercultural challenge in providing dignified care is aggravated by the lack of insight in the ethical aspects of intercultural care, combined with a lack of ethical guidelines for health care practice. Moreover, international literature lacks insight in the care experiences from the perspective of ethnic minority patients themselves. Nevertheless, such insight is crucial in finding an answer to the fundamental question on how to provide good intercultural care.

We aimed to fill this gap by performing a qualitative study on the intercultural maternity care experiences from the perspective of female Islamic patients themselves. Female Islamic patients are especially vulnerable when receiving care during this perinatal period. The Grounded Theory approach is used for the data collection and data analysis. Semi-structured interviews are conducted with female Islamic patients, midwives and gynecologist in Flanders. The interview guides are based on previous systematic literature review (Degrie et al., 2017).

From the literature review, we have learned that the intercultural care encounter can be presented as a meeting of two different cultural contexts of care, as a dynamic process of establishing a meaningful care relationship between caregiver and patient and as a process of balancing between the two different cultural contexts of care. We also learned that this process of balancing between two cultural contexts of care is essentially influenced by various mediators such as: communication, the role of family members, the role of the hospital's organizational structure and the presence of humanity in care.

At the moment of the EACME's Annual Conference in September 2017, we will present the findings from our own empirical research, i.e. from semi-structured interviews (with appr. 25 patients, 10 gynecologists, and 10 midwives) and discuss how we can ethically reflect on these results in order to find an answer to the fundamental question on realizing dignified care in the intercultural hospital setting.

#### References

Degrie et al. BMC Medical Ethics (2017) 18:2 DOI 10.1186/s12910-016-0163-8

WHO, (2010) Health of Migrants - The way forward. Report of a global consultation. Madrid, Spain, 3–5 March 2010. <http://apps.who.int/iris/handle/10665/44336>.

### **The effect of nurses' ethical leadership and ethical climate perceptions on their job satisfaction**

*Dilek Ozden (1), Gulsah Gurol Arslan (1), **Busra Diker** (1), Salih Karakaya (2)*

*(1) Dokuz Eylul University, Nursing Faculty, Izmir, Turkey*

*(2) Ministry of Health, Tepecik Education and Research Hospital, Izmir, Turkey*

**Introduction:** The development of ethical leadership approaches plays an important role in achieving better patient care. Although in various areas there are studies on the effect of the ethical leadership perception on the ethical climate, in the nursing literature there is a gap related to studies on this issue.

**Objective:** This descriptive and cross-sectional study aimed to determine the effect of nurses' ethical leadership and ethical climate perceptions on their job satisfaction.

**Method:** The study sample comprised 285 nurses working in the internal diseases, surgical and intensive care units of a university hospital and a training and research hospital in Izmir, Turkey between May 1 and December 31, 2016. Data were collected using the Personal Information Form, Ethical Leadership Scale (ELQ), Hospital Ethical Climate Scale (HCS) and Minnesota Satisfaction Scale (MSQ). While the independent sample T-Test, ANOVA, Mann-Whitney U test and Kruskal-Wallis test were used to analyze the data, the correlation analysis was used to determine the relationship between the scales.

**Results:** The participants' mean age was 32.85±7.26. Of them, 87.7% were female and 72.6% had a bachelor's degree. The participants' mean scores were 59.05±14.78 for the ethical leadership, 92.62±17 for the ethical climate, and 62.15±13.46 for the job satisfaction. The correlation between the participants' ethical leadership and ethical climate mean scores was moderately positive and



statistically significant ( $r=+0.625$ ,  $p=0.000$ ), it was weak but statistically significant between their ethical leadership and job satisfaction mean scores ( $r=+0.461$ ,  $p=0.000$ ) and it was moderately positive and statistically significant between their ethical climate and job satisfaction mean scores ( $r=+0.603$ ,  $p=0.000$ ). Of the participants, those who were female, had children, had a bachelor's or postgraduate degree had statistically significantly higher ethical leadership mean scores ( $p < 0.05$ ). The participants working in the university hospital obtained higher mean scores from the ethical leadership ( $63.28 \pm 14.40$ ) and ethical climate scales than did those working in the training and research hospital ( $96.27 \pm 15.44$ ). The difference was statistically significant ( $p < 0.05$ ). As the participants' length of service in profession increased, so did their perceptions of ethical climate. The difference was insignificant. The participants whose length of clinical service was longer had statistically significantly higher perceptions of ethical leadership and ethical climate ( $p < 0.05$ ). The participants working in the internal diseases units obtained higher mean scores from the ethical leadership ( $63.92 \pm 13.56$ ) and ethical climate ( $96.64 \pm 14.48$ ) scales than did those working in the surgical and intensive care units, and the difference was statistically significant ( $p < 0.05$ ). As the participants' satisfaction with their occupations and relationships with their colleagues increased so did their ethical leadership, ethical climate and job satisfaction mean scores, and the difference was statistically significant ( $p < 0.05$ ).

Conclusion: The participants' ethical leadership, ethical climate and job satisfaction levels were moderate, and there was a positive relationship between them. The participants' perceptions of ethical leadership were influenced by their educational status, workplace, and length of service.

### **What sustains nursing students' delivery of dignity in care? Preliminary findings of a critical discourse analysis of online solicited diaries**

*Sheila Douglas (1)*

*(1) University of Dundee, UK*

Background: Pedagogical moments appear to be important in the ongoing personal and professional development of the nursing student (van Manen 1991). A pragmatic review of evidence to support teaching and learning strategies that promote the delivery of dignity in care by nursing students identified that pedagogical moments were characterised as emotionally significant events that cause the nursing student to re-evaluate their perspective of good nursing care. As such these can be both positive and negative learning experiences in the clinical setting and appear to be cumulative throughout the placement journey (Corley, 2009, Murphy, Jones, Edwards, James, Mayer 2009, Vanlaere, Timmerman, Stevens, Gastmans 2012).

Research Aim: This study aims to deepen understanding of the characteristics of the pedagogical moments in clinical practice placements for nursing students. A second aim is to inform experiential learning and teaching in ethics.

Methodology and Method: Critical Discourse Analysis will be undertaken on data collected from nursing students while in clinical practice placement. van Leeuwen's (2008) analytical framework will be utilised. This framework establishes a 'recontextualisation chain' as it is uncovered within the nursing students' data. The framework affords several perspectives that will be used for analytical induction e.g. legitimisation of the practice, the space in which the practice takes place, all

of which relate closely to the socialisation process of nursing students on their personal, professional journey. Further theoretical stances offered by Corley (2002) and Gastmans (2013) will be integrated for their analytical potential in this complex area of care.

Data will be collected from online solicited diaries by undergraduate nursing students while on clinical practice placement. Follow-up semi-structured interviews will be conducted with a sub-sample of participants to examine themes emerging from the diaries more deeply, and explore emerging themes with the participants.

Conclusion: This paper will explore preliminary findings from the critical discourse analysis. Early themes elicited from the data analysis will relate to the theoretical framework. Questions will be posed regarding potential alignment with other theoretical and conceptual foundations that may offer an explanation of the emerging themes.

#### References

- Corley M C (2002) Nurse moral distress: A proposed theory and research agenda Nursing Ethics 9(6):636-650
- Gastmans C (2013) Dignity- enhancing nursing care-a foundational ethical framework Nursing Ethics 20(2): 142-9
- Murphy F Jones S Edwards M James J Mayer A (2009) The impact of nurse education on the caring behaviours of nursing students Nurse Education Today 29:254-264
- Vanlaere L Timmermann M Stevens M Gastmans C (2012) An explorative study of experiences of healthcare providers posing as simulated care receivers in a 'care-ethical' lab. Nursing Ethics 19(1):68-79
- van Leeuwen T (2008) Discourse and Practice: New tools for critical discourse analysis Oxford Oxford University Press
- van Manen M(1991) Reflectivity and the pedagogical moment: The normativity of pedagogical thinking and acting. Journal of Curriculum Studies 23(6): 507-537

### **Discourses on harm: Findings from a mixed methodology inquiry into incident and serious incident reporting in UK acute and community trusts.**

Hilary Engward (1)

(1) Anglia Ruskin University, UK

Patient harm is a recognised aspect of health care work, and whilst the reporting of incidents is improving, little is known about how the concept of harm is understood by health professionals. Using mixed methodology, concepts of harm and understandings of the incident reporting process across 3 acute care NHS organizations in the UK was explored. Findings indicate four recurring themes: Firstly, how staff manage grey areas of care work through the classification of incidents, particularly those that do not fit into pre-set policies. Secondly, how incident reporting is managed to meet the demands of others in relation to externally driven/mandatory requirements. Thirdly, professional/ disciplinary tribalism and lack of staff engagement, leading to a critical bystander approach and the questioning/ blaming of others actions/non actions. Fourthly, limited learning from incidents leading to negative engagement and limited learning for the incident reporting process. Taken in isolation each theme represents learning and development for organisations, and taken as a whole, the patterns indicate

disconnect between processes of understanding harm/s, the reporting of harm/s and learning as a result of reporting. The paper concludes by suggesting how harm and the incident reporting process can be better understood across organisations and professions in order to develop safer and consistent practices.

### **Developing ethical competence in Red Cross University College of Nursing in Madrid**

*Marta Mas Espejo (1), Rosa Pulido Mendoza (1)*

*(1) E.U.E. Cruz Roja Madrid*

Introduction: Nursing schools are responsible to promote ethical behavior among their students, in order to get future good professionals. The Red Cross University College of Nursing in Madrid profited the reforms needed in higher education due to the Bologna process to ensure that their students had a significant learning in the development of ethical competence in the new curriculum.

Objective: The aim of this paper is to describe the instructional design used in the Red Cross University College of Nursing in Madrid, to promote ethical behavior and interest in this field during the nursing degree courses, by introducing classroom activities in the theoretical subject and developing the transversal competence of 'ethical commitment' as a vehicle for integrating ethical theory and practice.

Method: The instructional design was planned following the ADDIE model, a systematic method consisting of five phases: analysis, development, implementation, and evaluation.

Instructional design:

Analysis: in this phase, it was necessary to evaluate the design of pre-Bologna curriculum, to ascertain the difficulties and needs of improvement in teaching ethics in the new program. As a result, we detected some problems in ethics approach who needed to be solved in the new curriculum, especially the difficulties of teaching theoretical concepts in the subject 'ethical care' and the lack of evaluation about ethical learning in clinical practice.

Design: In this point, the 'ethical commitment' competence was included into the competency-based training map designed for the curriculum. The subjects that participated in the development of this competence were the subject 'ethical care' from first-year and the clinical practice subjects from second, third and fourth year. For each subject, there were defined the knowledge, skills, and attitudes necessities, and there were set the learning outcomes to achieve them.

Development: In the development phase, teachers established contents and procedures and created materials for teaching and evaluation.

Implementation: The progressive implementation of the design was started in 2010, in the first year of the new nursing degree, and continued until the end of the promotion in 2014. The initial plan is still being implemented, with slight modifications of improvement. A complete and deeper review is planned for 2018.

Evaluation: Because the design is still in the implementation phase it is not possible to offer explicit results. However, both students and teachers demonstrate the proper functioning of the approach to ethics in the new curriculum through satisfaction surveys and the academic results.

Conclusion: Although the first results of the new design suggest a great advance compared with the previous approach of ethics, it would be necessary to finish the implementation in order to confirm a real improvement in teaching quality.

### **Discrimination on demented people in hospital settings: A scoping review**

*Melina Evripidou (1), Evridiki Papastavrou (1)*

*(1) School of Health Sciences, Department of Nursing, Cyprus University of Technology, Limassol, Cyprus*

Introduction: Although, universal declarations on the promotion of patient's rights emphasize the importance of non-discrimination in the provision of care, evidence reveals that demented people are often unrecognized.

Aim: To examine if any discrimination occurs, for demented people, in hospital settings.

Methods: We have conducted a scoping review of published studies in four data bases CINAHL, PsycArticles, Pubmed and Cochrane. The review conducted between October and November 2016, using various combinations of the following key-words "discrimination", "care", "patients", "dementia", "cognitive impairment" and "human rights". The inclusion criteria were set for studies to focus on discrimination in hospital settings. No restrictions were set for research design or year of publication.

Results: A total of 1105 titles were screened and 24 articles were eligible for analysis. Studies revealed that chronic patients, such as dementia, receive less care and money, than acute patients. Demented patients are frequently victims of physical restraints, mistreatment and sedative medications. Their consent and preferences are underestimated. Operations in demented people are often replaced by conservative treatment or minor operations and treatment is lessening, as well. Furthermore, poor quality of health services and care, due to structural and organization factors, lack of time for patients and information about their diagnosis, the absence of palliative care and shortcomings in training, were described as discrimination, in hospital settings. Gender and sociocultural level were described, by health providers, as factors of discrimination. Studies revealed that the staff is more tolerant of men idiosyncrasies than women.

Conclusion: Discrimination in hospital settings violates the principle of justice and equality. We need to emphasize this theme, so as to promote the moral practice and the positive approach of stigma among health providers.

**Learning from hospital interpreters about cultural issues related to advance care planning and end-of-life discussions**

*Anne Marie **Fabri** (1), Barbara Hayes (1), Maria Coperchini (2), Rafatullah Parkar (3), Zoë Austin-Crowe (4)*

*(1) Northern Health, Victoria, Melbourne, Australia*

*(2) Western Health, Victoria, Australia*

*(3) Monash Health, Victoria, Australia*

*(4) Department of Health & Human Services, Victoria, Australia*

Background: Advance care planning (ACP) is a growing research area but people from culturally and linguistically diverse (CALD) backgrounds are under-represented in this research. International research evaluating ACP by CALD communities reports a generally lower uptake, with some barriers identified. Research within the Australian culturally diverse population is very limited.

Study aim: The aim of this qualitative study is to better understand, through the experiences and insights of hospital interpreters, how people from CALD communities might respond to ACP and end-of-life discussions.

Methods: Hospital interpreters from five Melbourne metropolitan health services were recruited for in-depth semi-structured interviews that explored the question, 'What can be learned from hospital interpreters about cultural issues related to advance care planning and end-of-life decision-making?' Hospital interpreters were expected to have extensive experience of discussions about treatment limitations and end-of-life care, for the cultures that they interpret for. They were also expected to have personal experience of a culture. Interviews explored how people, within the interpreter's language group: discuss death and dying; make decisions about end-of-life care; and respond to ACP discussions. Thirty-nine interpreters, representing 22 language groups, were interviewed. Analysis of the transcribed interviews used qualitative description.

Findings: Thematic analysis identified three major themes: (1) moral difference; (2) health and death literacy; and (3) diversity within culture.

Conclusion: A values based approach to ACP is recommended as a way to capture the person's individual values and beliefs. Health and death literacy have been identified as areas that may be over-estimated; areas that can be addressed and improved, if recognised. Health and death literacy is a particular area that needs to be assessed and addressed as a pre-requisite to ACP discussions.

**Giving information to family members of patients in the intensive care unit: Iranian nurses' ethical approaches.**

Mansoureh A Farahani (1), Mina Gaeeni (2), Nooreddin Mohammadi (1), Naima Seyedfatemi (1)

(1) Faculty of Nursing and Midwifery, Iran University of Medical Sciences, Tehran, Iran.

(2) School of Nursing and Midwifery, Qom University of Medical Science and Health Services, Iran

Receiving information related to patients hospitalized in the intensive care unit is among the most important needs of the family members of such patients. When health care professionals should decide whether to be honest or to give hope, giving information becomes an ethical challenge.

We conducted a research to study the ethical approaches of Iranian nurses to giving information to the family members of patients in the intensive care units. This research was conducted in the intensive care units of three teaching hospitals in Iran. It employed a qualitative approach involving semi-structured and in-depth interviews with a purposive sample of 12 nurses to identify the ethical approaches to giving information to family members of the intensive care unit patients. A conventional content analysis of the data produced two categories and five subcategories. The two categories were as follows: a) informational support, and b) emotional support. Informational support had 2 subcategories consisting of being honest in giving information, and providing complete and understandable information. Emotional support in giving information had 3 sub-categories consisting of gradual revelation, empathy and assurance. Findings of the study indicated that ethical approaches to giving information can be in the form of either informational support or emotional support, based on patients' conditions and prognoses, their families' emotional state, the necessity of providing a calm atmosphere in the ICU and the hospital, and other patients and their families' peace. Findings of the present study can be used as a basis for further studies and for offering ethical guidelines in giving information to the families of patients hospitalized in the ICU.

**Four cases of conscientious objection to provision of abortion care in Europe**

Valerie Fleming (1), Beate Ramsayer, Teja Zaksek

(1) ZHAW Zürcher Hochschule für Angewandte Wissenschaften, Winterthur, Switzerland

While abortion has been legal in most developed countries for many years, the topic remains controversial. A major area of controversy concerns women's rights *vis a vis* the rights of health professionals to opt out of providing the service on conscience grounds. Although scholars from various disciplines have addressed this issue in the literature there is a lack of empirical research on the topic. This paper does not seek to challenge abortion laws but rather provides an analysis of four cases of conscientious objection on religious grounds to performing abortion-related care by midwives in different Member States of the European Union, two of which have resulted in legal action. Two of these cases resulted in the objections being overruled and the other two resulted in them being upheld.

These cases show, that as well as the laws of the respective countries and the European Union, professional and church law each played a part in the decisions made. However, support from both professional and religious sources was inconsistent both within and between cases. The authors

conclude that there is a need for clear guidelines at both local and pan-European level for health professionals and recommend a European wide forum to develop and test them.

### **Responsible leadership in an ethical and caring science perspective**

***Berit Foss** (1), **Katie Eriksson** (2), **Dagfinn Nåden** (1)*

*(1) Oslo and Akershus University College of Applied Sciences, Norway*

*(2) Åbo Akademi, Department of Caring Science, Finland*

The purpose of this presentation is to show a theoretical model of responsible leadership developed in an ethical and caring science perspective. Instrumental and economic discourses can result in a technological and artificial understanding of being. Therefore, present is a basic research study exploring core ontological questions pertaining to what ethical leadership is. The material is dictionaries, texts by Emmanuel Levinas (1906-1995) of responsibility and texts of Hans-Georg Gadamer (1900-2002) about understanding.

The study shows that leadership is part of the human existence and entails giving the human substance movement and direction. Leadership is understood as something of an eternal and lasting nature within the human being. In contrast the administrative tasks remain routines that are continually modified depending on the time and context in which they are found. Leadership becomes responsible leadership by assuming responsibility for the Other and by understanding responsibility for caring as the subject matter. This is to promote the human being's natural care for others, and thereby maintaining one's own and others dignity, facilitating the human being's real determination. The subject matter in a caring science perspective is to alleviate suffering and enhance life and health in a spirit of love as well as protect human dignity. Responsible leadership is to give one's own, and others' responsibility impetus and direction towards others' vulnerability and suffering. This is to serve in humility and proxy. The theoretical model finds its ethical strength in the fact that power lies with the Other, and in a clinical context the Other is the patient. Leadership in a clinical context is therefore to manage and serve the interest of the patient. To lead oneself and others to responsibility for the vulnerable and suffering patient is to protect human dignity in serving with love and care.

### **Nurse retention: Ethical issues in the decline of migration of Spanish nurses 1999-2007**

***Paola Galbany-Estragués** (1)(2), **Sioban Nelson** (3)*

*(1) Faculty of Nursing, University of Toronto, Canada*

*(2) Universidad Autónoma de Barcelona, Spain*

*(3) University of Toronto, Canada*

**Aim:** To reveal factors correlating with the decrease of migrations of Spanish-trained nurses from 1999 to 2007 and to analyze their relationship with the ethical nurse recruitment and retention defined by the International Council of Nurses.

**Background:** Nursing brain drain is a major concern for countries including Spain. Beginning in the 90s a significant number of Spanish-trained nurses has emigrated. However, from 1999 to 2007 there was a sharp decline in migrations, raising questions about factors promoting the retention of nurses.

**Introduction:** Nurse migration from Spain beginning in the 90s was facilitated by changes in education, international relations and the labour market. While numbers remained high, from 1999 to 2007, the yearly rate of applications dropped significantly, coinciding with a drop in nursing unemployment. We ask what social, economic and policy factors could be related to these drops.

**Methods:** We used publicly available statistics in order to test three hypotheses: that the drop in migration applications and unemployment coincided with 1) a drop in the number of nursing graduates, 2) an increase in the number of hospital beds and/or of hospitals, and/or 3) an increase in the ratio of part-time nursing contracts.

**Results:** Our analysis disconfirms the first two hypotheses and confirms the third. The drop in migration applications and nursing unemployment coincided with an increase in part-time contracts.

**Discussion:** The greater availability of part-time contracts seems to have encouraged nurses to remain in Spain, despite working conditions that were less favourable than those offered abroad. Future qualitative research with nurses would allow us to test this interpretation.

**Conclusion:** The confirmation of our first two hypotheses would have implied the existence of positive and education and health policy aimed at the retention of nurses (reducing job seekers and increasing jobs). We have shown that neither of these proactive paths was taken. Rather, the path taken reduced job security for nurses, who seem still to have preferred to remain in their home country, at least temporarily. International Council of Nurses in its ethical nurse recruitment and retention advocates access to the full employment of nurses as one of the keys to provide quality of care.

**Implications for nursing and Health Policy:** Paradoxically, worsening labour conditions may have helped retain nurses in Spain at the turn of the millennium. However, other research has shown serious consequences for nurses' quality of life and patient care when working conditions are unstable. Additionally, the retention was only temporary, because migration again began to climb at the beginning of the financial crisis in 2007. Far from recommending a shift toward more part-time contracts in order to stop nursing brain drain, we suggest instead that education and health policymakers consider proactive policies and ethical nurse recruitment and retention to adjust the balance between supply and demand without decreasing the quality of available positions.

### **Investigating ethical issues in palliative care examined within the Shia Islamic Bioethics paradigm**

***Nargilya Gasanova (1)***

*(1) King's College, London, UK*

This research project engages various western bioethical assumptions from a uniquely Shia Islamic perspective. This work focuses on the moral foundations of how various biotechnological and biopharmaceutical methods extend life for the elderly population and individuals living with chronic incurable diseases. This research presents a critical account of lesser-known alternatives that go beyond the standard 'quality and quantity of life' conversations in ethical dilemmas surrounding terminal or palliative sedation. Given the rapidly increasing need for palliative care in our diverse and aging population, additional new ethical perspectives are not only a crucial contribution to our academic knowledge, but also to the healthcare practitioners, such as nurses, working with these patients and their family members.



While the predominant voices in the religious bioethical conversations have traditionally been based on the Christian and Jewish faith traditions, the addition of Islamic voices and viewpoints are needed now more than ever. Considering that Islam is the world's second largest and fastest growing religion, including here in the United Kingdom, our ethical understanding and engagement is severely lacking and has not kept pace with the realities of the world.

One of the most exciting and important new bioethical voices to emerge in recent years comes from the Shia Islamic community. Despite being a minority group within Islam, the Shia perspective (practiced in countries like Iran and Lebanon) offers an important contribution, especially in the fields of the assisted reproductive technologies. Though there is a rather strong precedent against euthanasia amongst almost all of the religious groups, letting die is considered a morally acceptable practice within the Shia Islamic bioethics. More complex ethical dilemmas around the debate over withdrawing nutrition and hydration, in addition to the Shia theological process on producing new rulings and regulations and the notion of *ijtihad* will be discussed. The unsettled debate over brain death, that is, what exactly is defined as a brain dead patient is a prime example of the limited scholarly work in this area, as well as room for research. Since religion can be a crucial aspect of life, particularly carrying a special significance with the end-of-life decisions, critical engagement with the faith is essential for nursing ethics if we are to truly care for our patients, their families, and loved ones.

#### **Nursing professional identity: A survey study conducted by students**

Andrea Gazzelloni (1), *Francesca Maria Meloni* (1), *Valentina Pizziconi* (1), *Monica Venanzi* (1), *Rebecca Casciaro* (2), *Germano Cianetti* (2), *Adele Carpinelli* (2), *Giuliana D'Elpidio* (1)

(1) *Bambino Gesù Children's Hospital, IRCCS, Rome, Italy*

(2) *University of Rome Tor Vergata, Rome, Italy*

**INTRODUCTION:** Becoming a good nurse is a mandatory goal for each nurse. It is a daily challenge for both new and experienced nurses but also for students. On one hand, nurses have the responsibility to maintain the highest level of professional integrity and quality not only to protect patients and their families but also to positively influence nursing students. In fact, students learn how to become good nurses if they really experience that from all nurses they meet during their training. On the other hand, students have the responsibility to prepare themselves to reach the ambitious goal to become a good nurse at the end of their training. Furthermore, students are interested in knowing about what kind of life they are supposed to live as nurses and if their expectations will be met or failed. For this reason, it could be useful to take a "general picture" of nurses who work every day into the teaching hospitals. In particular, professional identity can be considered one of the first aspects to take into account to better understand in which way nurses could influence students during their daily practice.

**METHODS:** Twenty nursing students attending the second year at the University of Rome "Tor Vergata" conducted a survey study to investigate general and professional characteristics and to gain more information about the level of nursing professional identity.

Authorization was obtained from Hospital Medical Direction. An anonymous structured questionnaire, including general information (such as sex, age, marital status, children, free-time activity, familiar support, reason for having chosen to become nurse, health professionals in family etc.) and

professional information (such as university degree, other courses, level of satisfaction regarding different aspects of their job, if they would suggest to become a nurse, if they would choose again this job etc.) was administered with personal consent.

**RESULTS:** Seven-hundred and twenty two questionnaires were distributed. A descriptive statistical analysis was performed. Preliminary data, based on 334 questionnaires, are: nurses were mainly female (80%); mean age: 37,11ys (SD 8,49); health professionals in family: 15,87%; nursing as first choice: 72,16%; family support: 93,71%; importance of empathy: 94,91%; importance of both human and technical requirements: 94,88%; repeating nursing as first choice: 84,73%; recommending to become a nurse: 79,64%; level of general satisfaction: 64,97%.

Results were compared with data from questionnaires filled in by the same students. They discussed differences and similarities between their initial personal and family background and found results.

**CONCLUSIONS:** Professional identity is a delicate and complex topic that involves many aspects and it is an essential part that consistently influences the personal attitude to reach the best nursing practice.

### **Validity of the Italian Code of Ethics for everyday nursing practice**

*Paola **Gobbi** (1), Maria Grazia Castoldi (2) and Rosa Anna Alagna (2), Lorena Marioni (3), Claudia Passoni (4), Debora Rosa (5), Giovanni Muttillio (6), Miriam Magri (7), Franco A Carnevale (8)*

*(1) Agenzia di Tutela della Salute della Brianza, Monza, Italy; Collegio IPASVI Milano-Lodi-Monza e Brianza*

*(2) Azienda Socio Sanitaria Territoriale Ovest Milanese, Italy*

*(3) Azienda Socio Sanitaria Territoriale Santi Paolo e Carlo, Italy*

*(4) Istituto Europeo di Oncologia, Milan, Italy*

*(5) Fondazione Don Carlo Gnocchi Onlus, Milan, Italy*

*(6) Azienda Sanitaria Locale di Teramo; Collegio IPASVI Milano-Lodi-Monza e Brianza*

*(7) Collegio IPASVI Milano-Lodi-Monza e Brianza, Italy*

*(8) Mc Gill University, Montreal, Canada*

Aim: Identify ethical problems in nursing cases 2. Analyze and discuss professional behaviors in the light of professional ethical principles and ethical codes 3. Apply a method for discussion of cases in the field of ethics.

This project was conducted by the IPASVI Nurses Council of Milan Lodi Monza Brianza in Italy. The Council was invited to analyze the 2008 draft of the new Code of Ethics for Nurses in Italy. The research question addressed by this project was: Is the Council's Code a valid or useful decision-making instrument for nurses when they are faced with ethical problems in their daily clinical practice?

Methods: A series of focus groups were organized to analyze specific ethical problems in the form of eleven case studies from 2009 to 2015. The analysis was conducted by using sections of the Code relevant to the problem being examined; as well as other documents chosen according to the topic being discussed.

Results: Each focus group had a specific theme and nurses participated freely in the discussions according to the clinical competencies they developed through their practice in a specific field. The answer to the research question posed for this investigation was predominantly affirmative. Many sections of the Code were useful for discussion and identifying possible solutions for the ethical problems presented in the eleven cases.

Conclusion: We conclude from these findings that the Code of Ethics for Nurses in Italy can be a valuable aid in daily practice in most clinical situations that can give rise to ethical problems.

### **Elaborating a policy concerning ethics: Role of caregivers**

Simon Godecharle (1)

(1) *Emmaus, Mechelen, Belgium*

Within the daily health care practice various, sometimes even contradictive, perspectives are voiced concerning a wide range of topics, for example euthanasia, abortion or the use of restraint and seclusion within psychiatric care. Elaborating an ethics policy in a context of such diversity proves to be challenging. During this process, there is a vital role for the ethicist. He or she needs to consider both the perspectives from the daily health care practice and those of policy and management. In line with the fact that several elements are of importance throughout ethical reflection, also various steps must be taken when elaborating an ethics policy. In the discussed approach, I strongly focus on involving the caregivers themselves.

Firstly, we need to examine the original experience of moral conflict. The caregivers are confronted with a (complex) situation that is not in line with their moral perspectives. We need to focus on the specific action, theme, case or question that caused the various caregivers involved to, for example, feel indignant. There might also be a combination of various elements. This experience of moral conflict forms the starting point of our reflection. Secondly, we need to clarify which people are directly and indirectly involved: patient him- or herself, other patients that might live together with this patient, nurses, doctors, family, etc. These relevant stakeholders might all feel the impact of a decision. We also need to assure ourselves that we have all the relevant information concerning the original experience of moral conflict, including the possible legal perspectives. Thirdly we confront the various perspectives and argumentations, as well as the moral intuitions on which they are based, in an open and genuine dialogue. This dialogue however has to fulfill certain requirements.

When we make a concrete decision, it is important to ask the caregivers themselves how they consider this decision. Do they feel that their perspective is sufficiently recognized? When caregivers, for example nurses, are granted a vital role during this entire process, we can aim to reach a policy that is not forced top down, but is rather the result of a bottom up and continuous process.

The process of elaborating an ethics policy falls back on the shared values in an organization. These values operate as a frame in which this process can take place. During the process we continuously need to consider the vital role of proportionality, and Paul Ricoeur's distinction between the "*meilleur humain possible*" and the "*meilleur humain desirable*".

**The perspective of people with long-term ventilation (and their relatives) on their nursing care situation at home**

*Christiane Gödecke (1), Helen Kohlen (1)*

*(1) Philosophisch Theologische Hochschule Vallendar, Germany*

Background: It is becoming increasingly common to provide mechanical ventilation at home. More and more patients are discharged from clinics, and life expectancy for those on a ventilator is higher. Specialized nursing services (intensive care, mechanical ventilation) provide qualified nursing staff for the individuals concerned on an up to 24-hour basis. Families/individuals with home mechanical ventilation can also act as employers in their own right and hire nursing staff or, with medical certificates, employ helpers without specialist training.

Objective: The objective of this research is to map the perspectives of persons with home mechanical ventilation (and of their relatives) with regard to their nursing care situation. It examines the interaction between the persons affected (relatives), staff and technology within the theoretical framework of the Ethics of Care and approaches of the philosophy of technology.

Method: The data was gathered in 20 interviews conducted with persons with long-term ventilation and their relatives in a home mechanical ventilation environment. Data analysis was carried out based on Grounded Theory.

Ethical considerations: The ethical committee of the German Society of Nursing Science approved this study.

Findings: Key categories within the findings are: "Becoming an expert," "Being able to communicate," "Always someone there," "The family in the background," "Between dependency and the desire to do things and decide things for oneself" and "Having a team." The central goal is the desire to live one's own life and take charge of one's fate.

Among others things, the findings show that a reversal of the asymmetry between the affected persons and nursing staff can occur. Moreover, the affected persons and their relatives become experts of their situation. Independence and self-determination play a greater role in the interviews than dependency. Confidence in the staff, the family, situational knowledge and the ability of the affected persons to communicate contribute significantly to security.

Conclusion: Both the staff and the technology involved have an influence on the domestic environment. Establishing a relationship with and confidence in the staff helps the affected persons to achieve the goal of self-determination, while the technology allows independence. Technology requires 'designers' who adapt it to foreign environments. Both, the staff and the technology are factors enabling the individuals concerned to take charge of their own lives and to boost their quality of life.

**Innovation in ethics: Hospital without pain in little procedures respecting the principle of beneficence justice and autonomy**

Encarna Gomez Gamboa (1)

(1) Hospital Sant Joan de Déu, Barcelona, Spain

Introduction: Sant Joan de Déu Children's Hospital has opened an innovative line to incorporate the program "Hospital without pain in little procedures" as cures, punctions or the withdrawal of catheter. All initiatives go beyond pharmacological treatment to improve effect in emotions, such as fear, anxiety and decrease the perception of pain. The principles of justice beneficence and autonomy must always be respected in every procedure of the health care and to obtain a care centered in the person that does not focus only to the diagnoses and treatments. It is estimated that over 300.000 patients will benefit from this program every year in our hospital.

Aims: Prevent and minimize the pain and discomfort in children when they are subjected to potentially painful clinical procedures. To make known an exemplary real situation through a video that shows the professional care ethics.

Methodology: The strategies used by professionals of the Sant Joan de Déu Children's Hospital are based on four larger areas:

1. The program includes a wide range of pharmacological and non-pharmacological measures tailored to each child.
2. The effectiveness of distraction as a powerful tool to combat the fear and pain, by "Kit distraction": and so directing attention away from the pain and focus on pleasing elements. Everything is useful: talk to the kid, singing pampered. ... our professionals have a box with small toys for the children of all ages to entertain the patients.
3. The presence of parents: family are actively involved and present during the procedures. Health professionals encourage parents to hold their children with comfort positions, facilitating the development of the procedure and combat anxiety of the patient, family and professionals.
4. The positive reinforcement: Reinforcing positive behavior of the child is essential to streamline procedures and achieve the objectives of reducing pain and anxiety during procedures. In this sense, throughout the care process is carried out to verbal reinforcement of the actions of children, encouraging them during painful procedures or that generate anxiety.

Results:

- The children's game and other strategies provide relaxation and adaptation in the children for little procedures.
- Increase good relation with patients and families.
- Good experience. It's effective to combat anxiety, fear and pain.
- The patients feel real stars.
- Little procedures are more successful when use holistic treatments.

Conclusions: Professional's implication is very important in these points:

- Hospital works transversely through a network of professionals who help to meet the needs of patients and work initiatives proposed.
- Professionals have training programs to increase knowledge.
- The Professionals systematically apply all the resources available to assess whether patients are suffering pain.
- Pain can occur in any process not only in the more complex interventions.
- Professionals use a language adapted to age and procedures of children.

### **Difficult and satisfying care for vegetative patients at home as an unavoidable duty: A qualitative study**

*Fateme Goudarzi (1), Heidarali Abedi (2), Kouros Zarea (3), Fazlollah Ahmadi (4)*

- (1) Nursing and Midwifery School, Lorestan University of Medical Sciences, Khorramabad, Iran*
- (2) Faculty of Nursing and Midwifery, Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, Iran*
- (3) Nursing and Midwifery School, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran*
- (4) Department of Nursing, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, Iran*

**Introduction and Objectives:** Patients who are in a vegetative state are completely dependent on others for their self-care because of a poor prognosis. On the other hand, because of the specific conditions of consciousness of these patients, there are different views and laws about the continuation and outcomes of caring for these patients. These different views can affect attitudes towards these patients and their continued care. Due to the absence of any studies about vegetative patients and their families in Iran, this qualitative study was conducted to determine and explain the dimensions of caring for patients in vegetative states.

**Methods and Materials:** The present qualitative study was conducted in some provinces of Iran from 2013 to 2015. Participants in the study were 22 people, including 17 family caregivers, 5 professional caregivers and hospital nurses. All of them entered the research through purposive sampling. Ethical considerations were respected in the sampling process. Data collection was conducted using unstructured face-to-face interviews, observation and field notes. Data collection continued until data saturation occurred and major themes became apparent. Content analysis was performed using the Lundman and Graneheim approach and the constant comparative technique. Guba and Lincoln's criteria were followed to ensure rigor in this qualitative data.

**Findings:** As a result of data analysis, the main theme of "difficult and unavoidable but satisfying duty" emerged, and its three sub-themes included "the obligation to care for the patient", "care as a difficult totality" and "caring with positive results". These three sub-themes had nine subcategories. These subcategories reveal that lack of specific care centers for these patients make the caring an unavoidable duty and obligation for the families. On the other hand, the various and great needs of the patients and the repetitive and time-consuming nature of these needs and tasks make this duty even more difficult. Nevertheless, home caregivers consider this task as satisfying.

**Conclusion:** What encourages the family caregivers and the families of the patients suffering from a vegetative state to care for them with as much strength and energy as they can muster is adherence

to the moral and ethical principles resulting from the Islamic values dominant in Iranian society. Therefore, in addition to taking advantage of this valuable background and context in Iranian families, the health system of the country needs to provide special support to these families in order to reduce their problems and difficulties in taking care of these patients and to prevent their families' exhaustion.

**Using a moral compass to navigate the 'Grey Areas': A content analysis of the Clinical Ethics Residency for Nurses (CERN) final essays**

*Pamela J. Grace (1), Susan M. Lee (2), Ellen M. Robinson (3), Martha Jurchak (2), Rev. Angelika Zollfrank (4)*

*(1) Boston College, USA*

*(2) Brigham and Women's Hospital, Boston, USA*

*(3) Massachusetts General Hospital, Boston, USA*

*(4) Yale-New Haven Hospital, Connecticut, USA*

The clinical ethics residency for nurses (CERN) was a US government funded project designed to create an ethics education model that aimed to increase nurse confidence in ethical decision-making and action and prepare bedside and supervisory nurses to serve as local and institutional ethics resources. The program used a multimodal educational curriculum of one eight-hour day for each of nine months. There were three separate cohorts of nurses over the three years of the program (2010-13). Participants were from a variety of settings. Details of the program itself have been published elsewhere. In this presentation we report on our content analysis of the themes emerging from the final essays. Participants were asked to reflect upon how the CERN experience had impacted them using their application essays as an anchor. In the application essays they had been asked to describe why they wanted to be considered for the program.

For the final or 'synthesis' essays, participants were asked to consider in what ways if any CERN had changed how they: approach and analyze ethical problems, communicate with others about ethical issues, and had developed new insights about themselves using examples. They were also asked to highlight the most important aspects of the program for them. Here we report preliminary findings. Using conventional content analysis the essays (N=65) were explored. The overarching theme, using a collage of participant words, is that they developed the ethical knowledge and skills that gave them a moral compass to navigate the many grey areas of decision-making that confront them in daily practice. Four major themes include: acquiring the frameworks and tools to clarify important elements of complex problems; using reasoning and ethics language to give voice to nursing and patient concerns as part of healthcare team; developing abilities to support colleagues, patients, and family; listening to the stories and concerns of others in the group. Finally, we discuss the implications for formal and ongoing ethics education.

## **Researching highly vulnerable populations: Ethical challenges and methodological answers**

*Maria Grypdonck (1) , Sofie Verhaeghe(1), Marijke Kars (2)*

*(1) Ghent University, Ghent, Belgium*

*(2) Utrecht University Medical Center, Utrecht The Netherlands*

At the 2015 Nursing Ethics Conference, Joan Tronto raised the question of the care ethical perspective on inclusion of participants in research. How acceptable is it, from a care ethical point of view to use persons for one's research and carrier goals?

For almost 30 years I have conducted qualitative research with patients with a chronic illness and their family members. Some of the populations consist of highly vulnerable persons. Most of the co-researchers were young nurses. In this presentation I will address how care can be taken to make the research acceptable from a care ethical perspective and what challenges need to be met.

Approaching persons in a state of deep suffering or other existentially challenging situations to put themselves at the service of others is not evident. Authenticity of the interviewers and researchers is necessary to avoid exploitation. In authenticity, the researcher can offer the subjects the benefit of knowing that their suffering serves a purpose.

The interviews give the participants a chance to tell their story and to be recognized in their suffering. For some of them, it is an almost unique experience. The researcher needs to balance his/her agenda in an asymmetrical way with the needs of the interviewees. The researcher needs to stay in his/her role of concerned interlocutor. A construction of the interview is sought that at the same time is satisfactory to the participant and not blurring the understanding of what the person lives through. Sometimes, issues are brought up that require discussion or intervention from a helping perspective. Usually this was done at the end of the interview. Patients always were offered the opportunities to seek contact with the researcher afterwards, and/or arrangements were made for follow up by the care providers or an external organization. If conflicts arose between the needs of the research and those of the participants, the needs of the participants were given priority.

The analysis is particularly challenging. It requires a subtle balance and alternation between going and feeling with and taking distance. Apart from the usual issues in detecting and uncovering the true story beyond social desirability and hiding, there is the challenge of doing right to the person.

Reporting the study in a way that understanding may increase is necessary to reach the goal of the study. It requires appropriate choices to reach this goal at the same time as the scientific objectives.

To do justice to the efforts made by the participants, the researcher has the responsibility to contribute to a change of the situation. Such research also entails the obligation of protecting the (young) researchers from the consequences of their being involved so closely with a person's difficult life.



## **The learning community care ethical coach: A place for growth and development of ethical knowledge**

*Maria Grypdonck (1,2), Madeleine Timmermann (1,3), Linus Vanlaere (4), Sibylle Verfaillie (1,5), Nele Janssens (1), Sarah Janssens (1,6)*

- (1) *sTimul Care Ethics Lab, Moorsele, Belgium*
- (2) *Ghent University, Belgium*
- (3) *Hospice Roosdonck, Roosendaal, The Netherlands*
- (4) *RHIZO, Kortrijk, Belgium*
- (5) *WZC Sint Jozef, Moorsele, Belgium*
- (6) *HOWEST, University College for Applied Sciences, Belgium*

In 2012 sTimul, an ethical care laboratory, started a learning community to “educate” care ethical coaches who could stimulate care ethical practice in care organizations and schools of nursing. Participants engaged in a four year trajectory. The staff consisted of three persons with ethical and/or nursing background. The trajectory consisted of communal sessions, individual homework and group work. The learning community continuously used interaction between (organized) experience, reading ethical literature, input from the staff and exchange among the members (both participants and staff) as its didactical model. In the course of the four year trajectory the input of the staff diminished, that of the participants increased. Reflection on the care ethical content of the interactions in the Learning Community itself was an important aspect of the learning experience.

The Learning Community Care Ethical Coach proved to be a fertile ground for care ethical growth as well as for developing care ethical knowledge and care ethical leadership.

The participants as well as the staff deepened their insights into care ethical practice as well as into (stimulating) ethical growth. By reflecting on and discussing experiences encountered in their work as in experiences that were created for the “course” (such as talking to patients about their experiences or observing in a waiting room), both participants and staff discovered the deeper meaning of care ethical concepts. In particular, the dimensions of the ethical competency, developed by Gallagher (2006) (ethical seeing, reflecting, knowing, doing, being) were further developed in a care ethical direction. Insights were developed concerning the role of a care ethical coach and the means that can (not) be used in stimulating care ethical practice. The Learning Community fostered care ethical growth in the members, enriched their personal knowledge, contributed to explicating personal knowledge and led to the development of declarative knowledge that can be shared with others and can be used and tested in discussion, research and practice. Participation in a learning community as the one discussed here, changes participants. Therefore it requires attention to the ethical aspects of what the learning community brings about. In order to achieve the reported results, the Learning Community needs to exhibit the characteristics of what van den Nieuwenhof and De Weerd (2006) refer to as the Didactics of Love: presence, humility, relatedness and discipline.

### References

Gallagher, A. 2006. The Teaching of Nursing Ethics: content and method. In: A. Davis, V. Tschudin & L. De Raeye (eds), *Essentials of Teaching and Learning in Nursing Ethics*, Churchill Livingstone, London, 2006, pp. 223-239.

Van den Nieuwenhof R, De Weerd S. 2006. Didactiek van de liefde: een pleidooi voor diepgaand leren in coaching, training en opleidingen. In: Hovelynck J, De Weerd S, Dewulf A, editors. *Relationeel organiseren : samen leren en werken in en tussen organisaties*. Leuven: LanooCampus. p 75-105.

**An explorative study of experiences of healthcare providers posing as simulated care receivers in a domiciliary care environment**

*Mieke Grypdonck (1) (2), Linus Vanlaere (1) (3), Nele Janssens (1)*

*(1) sTimul Care Ethics Lab, Moorsele, Belgium*

*(2) Ghent University, Belgium*

*(3) RHIZO, Kortrijk, Belgium*

To be able to think about what is ‘good care’ for domiciliary careworkers and organizations who provide care in people’s houses, sTimul experimented with an experiential learning method in domiciliary care. It’s a method with a highly physical component referred to as exposure and developed for educational and healthcare organizations.

We brought the care providers in a situation and a state where they are care dependent themselves. By doing this we aimed to deepen the understanding of (future) care providers about vulnerability in care dependent situations and increase their commitment in a way that does justice to the care-receiver.

**Methodology:** To gain insight into the method and the experiences of professional care providers in domiciliary care we chose for a method of qualitative research. The research makes use of the methods of grounded theory. We conducted 15 interviews over a period of 4 months. The interview started with the question: ‘How was it for you’.

The participants were asked to speak freely about their experiences in the position of a care receiver. We only intended to bring the participants in a narrative mode. All further questions asked were meant to discover the specific circumstances of the simulation and to explore the experiences of the participants in depth. We tried to get a reliable impression of feelings, thoughts and behavior of the participants and the specific meaning of the experiences for each individual participant. The students’ participation was explored from the viewpoint of the professional care provider, they were not interviewed.

**Outcome:** The overall result is that the training is confronting and has a deep impact for most of the participants. They identified strongly with the role and described the experience of care-dependency as very real. The study revealed three key-experiences that we would refer to as ex-propiation of the house (the strong impact of letting a stranger in your house), a feeling of staying in control versus being dependent (the feeling that you cannot control how things that once were your own domain are done differently), a feeling of being seen versus a feeling of being patronized (a feeling depending on the perception about care that was not asked for). The first was referred to as a nice feeling, the second was not.

While experiencing dependency caregivers also mentioned that they gained more insight in what their job is about and how they can make a difference for the care-receiver.

On behavioral level (change in practice) there were reported different degrees of change. Most of the professionals realize that attuning the care is important.

A first tentative conclusion is that this form of exposure for professionals in domiciliary care can contribute to more care-ethical practice. We'd like to present you some results of our study.

### **Hospital/clinical ethics committees' notion: An overview**

*Fatemeh Hajibabae (1), Soodabeh Joolae (2), Mohammad Ali Cheraghi (1), Pooneh Salari (3)*

*(1) Faculty of Nursing & Midwifery, Tehran University of Medical Sciences, Tehran, Iran*

*(2) Center for Nursing Care Research, Iran University of Medical Sciences; Iranian Academy of Medical Sciences, Tehran, Iran*

*(3) Medical Ethics and History of Medicine Research Center, Tehran University of Medical Sciences, Tehran, Iran*

**Background:** Hospital ethics committees (HECs) are designed to ensure proper clinical decision-making and are responsible for monitoring the ethical provision of services in hospitals. They also aim to assist patients and health care professionals without interfering in the physician-patient relationship. Hospital ethics committees help nurses deal with the ethical challenges raised during clinical practice. We have conducted a comprehensive literature review to provide a historical background of developing hospital ethics committees internationally and describe their functions and the role of nurses in the HECs.

**Methods:** This is the first part of a comprehensive literature review conducted between 2014Feb and 2016 Aug, by searching through scientific databases. We used the keyword Ethics committee, combined with hospital, clinic, institution, and nurses without a time limitation. We included all original and discussion articles, as well as other scientific documents. Of the whole articles and theses were found with these keywords; only 56 were consistent with the objectives of our study. In response to our review goals we divided our findings to three main categories; the inception of HECs in the world, the function of HECs and the role of nurses in HECs.

**Results:** According to the results, the Americas Region and European Region countries have been the most prominent considering the establishment of HECs. However, the majority of the Eastern Mediterranean Region and South-East Asia Region countries are only beginning to establish these committees in their hospitals. Three domains or functions are to be covered by hospital ethics committees in their ordinary work. First, the HEC needs to educate its members, hospital staff, and also patients about ethical issues. The second function of an HEC would be to cooperate in the development and revision of various hospital policies and guidelines to facilitate service provision by hospital personnel. In the end, the third function of a HEC which is supposed to be taken into account is the task of ethical case analysis. Nurses may refer a case to the HECs, attend an educational session by the ethics committees, ask for support from the HECs, or serve as a member of the committees.

**Conclusion:** The results highlight the status and function of HECs in different countries and may be used as a guide by health policymakers and managers who are at the inception of establishing these committees in their hospitals. Due to their closeness to patients and their professional need for patient support, an ethics committee consult is periodically required to be called by nurses to have access to

demanded assistance to solve an ethical dilemma. Ethical issues ought to be regarded even more in nursing and nurses should be taught on ethical issues through ongoing education programs, in-service programs, patient care conferences, and academic courses.

**Life memories and the ability to act: The meaning of autonomy and participation for older people when living with chronic illness**

*Maria Hedman (1)(2), Ulrika Pöder (1), Anna-Greta Mamhidir (1)(2), Annika Nilsson (1)(2), Marja-Leena Kristofferzon (1)(2), Elisabeth Häggström (1)(2)*

*(1) Department of public health and caring science, caring science, Uppsala University, Uppsala, Sweden*

*(2) Department of health and occupational studies, health and caring science, University of Gävle, Gävle, Sweden*

Background: Autonomy as a concept signifies the people's liberty of choice and action [1], having the right to self-determination [2, 3] as well as, for example, being capable of rational decision-making [4]. Participation is defined in different contexts such as in regard to decision-making in healthcare [5], in functioning and disability including involvement in life situations and in society [6]. Risk of reduced autonomy and participation are indicated for older people in healthcare [7,8,9] and in everyday life when living with chronic illness [10,11,12]. To support their autonomy and participation, further understanding about how older people living with chronic illness describe the meaning of autonomy and participation is necessary.

The purpose of this study was to describe the meaning of autonomy and participation among older people living with chronic illness in accordance with their lived experience.

Method: The design was descriptive with a phenomenological approach [13,14]. Purposive sampling was used, and 16 older people living with chronic illness who lived in an ordinary home participated in individual interviews. Data collection and analysis was guided by Giorgi's phenomenological psychological method [13].

Result: The general essential structure contained one core constituent and three constituents describing the meaning of autonomy and participation to the older people living with chronic illness. The findings showed that the meaning of autonomy and participation emerged when it was challenged and evoked emotional considerations of the lived experience of having a chronic illness. It involved living a life apart, yet still being someone who is able, trustworthy, and given responsibility — still being seen and acknowledged. The meaning of autonomy and participation was derived through life memories and used by the older people in everyday life for adjustment or adaption to the present life and the future.

Conclusion: Autonomy and participation were considered in relation to older people's life memories from the past, in the present situation and for their future wishes. The core is essential and based on the present findings, ability or disability is of less importance than older people's thoughts concerning the meaning of everyday life. When caring for older people less use of labels of limitation, and more use of 'ability to act' in different ways are suggested.

Acknowledgement: The authors thank all the older persons who participated in the study.

Ethical approval: Ethical consideration and approval in accordance with the WMA Declaration of Helsinki were obtained from the Regional Research Ethics Committee in Uppsala Sweden (Reg.no. 2012/436). Each informant gave his/her informed consent before the interview and the informants' privacy and confidentiality were guaranteed.

#### References

1. Collopy BJ. Autonomy in long term care: some crucial distinctions. *Gerontologist* 1988; 28 Suppl:10-17.
2. Kant I. Grundläggning av sedernas metafysik (Groundwork for the Metaphysics of Morals). 1997, Daidalos, Göteborg.
3. Kant I. Kritik av det praktiska förnuftet (Critique of Practical Reason). 2004, Thales, Stockholm.
4. Kemp P. Etikens verden. In *Filosofi – Etik- Videnskabsteori (Philosophy - Ethics-Philosophy of Science)* (Bjerrum M & Lund Christiansen K ed.), 2001 Akademisk forlag, Copenhagen.
5. Thompson AG. The meaning of patient involvement and participation in health care consultations: a taxonomy. *Soc Sci Med* 2007; 64:1297-310.
6. WHO. *ICF International classification of functioning, disability and health*. 2008, Geneva, World Health Organization, <http://www.who.int>
7. Foss C, Askautrud M. Measuring the participation of elderly patients in the discharge process from hospital: a critical review of existing instruments. *Scand J Caring Sci* 2010; 24:46-55.
8. Aasen EM, Kvangarsnes M, Heggen K. Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. *Scand J Caring Sci* 2012; 26: 61-9.
9. Mangset M, Dahl TE, Førde R, Wyller TB. 'We're just sick people, nothing else': ... factors contributing to elderly stroke patients' satisfaction with rehabilitation. *Clin Rehabil* 2008; 22:825-35.
10. Fong T, Finlayson M, Peacock N. The social experiences of aging with a chronic illness: perspectives of older adults with multiple sclerosis. *Disabil Rehabil* 2006; 28:695-705.
11. Roy DE, Giddings LS. The experiences of women (65-74 years) living with a long-term condition in the shadow of ageing. *J Adv Nurs* 2012; 68:181-90.
12. Giddings LS, Roy DE, Predeger E. Women's experience of ageing with a chronic condition. *J Adv Nurs* 2007; 58:557-65.
13. Giorgi A. *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach*. 2009, Duquesne University Press, Pittsburgh.
14. Husserl E. *Idéer till en ren fenomenologi och fenomenologisk filosofi. (Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy)*. 2004, Thales, Stockholm.

#### **Students' perceptions regarding the third-year nursing ethics module at Shifa College of Nursing, Islamabad, Pakistan**

##### ***Farida Himat (1)***

(1) *Principal Islamabad Nursing College. Main campus Islamabad Medical and Dental College, Islamabad, Pakistan*

Aim: This study aimed to explore the perceptions of third year nursing students regarding the ethics module at Shifa College of Nursing, Islamabad, Pakistan.

Methods: Third year nursing students (n=26) completed a retrospective pre/post survey rating their knowledge before and after the ethics module. Focus group discussions (FGDs) addressed the importance of ethics teaching in nursing, the content, teaching and learning strategies of the module as well as whether the application of the concepts learned in the classroom were practiced in the clinical setting.

Results: Participants rated their knowledge higher in the post-test (4.00) than the pretest questionnaire (2.26) ( $p=0.003$ ). The main themes identified during the focus group discussions were: understanding their responsibilities towards the patient; an appreciation of the patient as a human being; applicability of the module to the clinical setting; the role of student nurses in ethical decision making in the clinical setting; and the teaching and learning strategies. The context of the nurse's practice was also identified as being important.

Conclusion: The participants valued the ethics module and its applicability to the clinical setting, but changes in the content of the module and the teaching and learning strategies were suggested.

### **Moral Sensitivity and its Dimensions in Iranian Nursing Students**

*Fariba Borhani (1), Abbas Abbaszade (2), Mohammad Javad Hoseinabadi-farahani (3)*

*(1) Medical Ethics and Law Research Center, Shahid Beheshti University of Medical Sciences, Tehran, Iran*

*(2) Department of Medical Surgical Nursing, School of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences and Iranian Academy of Medical Sciences, Tehran, Iran*

*(3) Department of Nursing, University of Social Welfare and Rehabilitation Sciences, Tehran, Iran*

As future providers of health services, nursing students should learn about ethical concepts over the course of their education. These concepts are currently taught in nursing schools, yet the degree of moral sensitivity in nursing students before entering clinical settings is a topic of controversy. This was a cross-sectional study on the nursing students studying for a bachelor's degree in Qazvin University of Medical Sciences selected through census sampling ( $n = 205$ ). Data were collected by Lutzen's Moral Sensitivity Questionnaire and analyzed through statistical tests using SPSS 16. The level of significance was  $P < 0.05$ . In order to conduct the study, permission was obtained from the Ethics Committee of Shahid Beheshti University of Medical Sciences.

The mean of moral sensitivity was found to be  $66.1 \pm 8.1$ , which is a moderate level. Of all the dimensions of moral sensitivity, "expressing benevolence" had the highest ( $16.9 \pm 4.04$ ) and "structuring moral sense" had the lowest ( $5.2 \pm 1.45$ ) mean scores. Among demographic variables, age was found to have a significant positive correlation with the score of moral sensitivity ( $r = 0.2, P = 0.01$ ). Nursing students are relatively familiar with the ethical concepts of patient care, but that does not seem to be sufficed, as moral sensitivity is an extremely crucial factor in care. It is therefore recommended that the necessary training be provided to develop moral sensitivity in nursing students both in educational and practical environments.

### **Moral sensitivity and moral distress in Iranian critical care nurses**

*Fariba Borhani (1), Abbas Abbaszade (2), Erfan Ghasemi (3), Mohammad Javad Hoseinabadi-farahani (4)*

*(1) Medical Ethics and Law Research Center, Shahid Beheshti University of Medical Sciences, Tehran, Iran*

*(2) Department of Medical Surgical Nursing, School of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences and Iranian Academy of Medical Sciences, Tehran, Iran*

*(3) Shahid Beheshti University of Medical Sciences, School of Paramedical, Department of Biostatistics, Tehran, Iran*

*(4) Department of Nursing, University of Social Welfare and Rehabilitation Sciences, Tehran, Iran*

**Background:** Moral sensitivity is the foremost prerequisite to ethical performance; a review of literature shows that nurses are sometimes not sensitive enough for a variety of reasons. Moral distress is a frequent phenomenon in nursing, which may result in paradoxes in care, dealing with patients and rendering high quality care. This may, in turn, hinder the meeting of care objectives, thus affecting social healthcare standards.

**Research objective:** The present research was conducted to determine the relationship between moral sensitivity and moral distress of nurses in intensive care units.

**Research design:** This study is a descriptive-correlation research. Lutzen's moral sensitivity questionnaire and Corley Moral Distress Questionnaire were used to gather data.

**Participants and research context:** A total of 153 qualified nurses working in the hospitals affiliated to Shahid Beheshti University of Medical Sciences were selected for this study. Subjects were selected by census method.

**Ethical considerations:** After explaining the objectives of the study, all the participants completed and signed the written consent form. To conduct the study, permission was obtained from the selected hospitals.

**Findings:** Nurses' average moral sensitivity grade was  $68.6 \pm 7.8$ , which shows a moderate level of moral sensitivity. On the other hand, nurses also experienced a moderate level of moral distress ( $44.8 \pm 16.6$ ). Moreover, there was no meaningful statistical relationship between moral sensitivity and moral distress ( $p = 0.26$ ).

**Discussion:** Although the nurses' moral sensitivity and moral distress were expected to be high in the intensive care units, it was moderate. This finding is consistent with the results of some studies and contradicts with others.

**Conclusion:** As moral sensitivity is a crucial factor in care, it is suggested that necessary training be provided to develop moral sensitivity in nurses in education and practical environments. Furthermore, removing factors that contribute to moral distress may help decrease it in nurses.

**Moral distress is the harsh feeling experienced by professional carers when they feel unable to act upon deeply held (professional) values and their personal view on what 'good care' should be**

*Sarah Janssens (1), Veronique Hoste (1)*

*(1) Howest, Bruges, Belgium*

The research group 'Ethics in care' of the Nursing Department of Howest University of Applied Sciences, Belgium, carried out a project on 'moral distress', in collaboration with Woonzorggroep GVO (a group of residential care homes in West-Flanders, Belgium). This project was made possible by the European Social Fund and the Flemish Government.

Semi-structured interviews were conducted with professional carers in elderly care to get a grip on the topic of moral distress. Using the method of appreciative inquiry, focus groups were held with registered nurses, nursing assistants, head nurses, logistic employees, occupational therapists, physical therapists... Instruments and guidelines were developed and tested in three care homes.

The outcome of this ESF-project is a website and a toolkit (guide and instruments) to detect, approach and handle moral distress in health care organizations on three levels: the organization level, the supervisor and team level and the individual level. The aim is to enhance moral resilience in coping with moral distress.

Chronically unresolved moral distress is related to

- reduced quality of care
- lower job satisfaction
- increased turnover and absenteeism
- physical, emotional, behavioral and spiritual effects on the individual level: (emotional- exhaustion, sleeping problems, rumination); feelings of anger, powerlessness, guilt, shame, depressive feelings; burn-out and compassion fatigue; disengagement; desensitization; restlessness; agitation; cynicism.

Moral distress is inherent in health care situations. It develops from the moral values and beliefs held by professional carers and their engagement to provide good care. Hence, it is not possible nor desirable to root out moral distress. Moral distress causes professional carers to reflect upon their actions and to re-evaluate the quality and the organization of the provided care. The discontentment caused by moral distress often results in positive changes (that benefit the patients). Awareness about moral distress is crucial, also in organizations that already foster ethical growth of their employees. Moral sensitivity and moral resilience are valuable characteristics of caretakers.

The researchers developed a toolkit that consists of a wide range of tools and suggestions (guide) on the individual, team, supervisor and organizational level. The organization is free as to which tools will be used, depending on the needs, wishes, possibilities and style of the company. The website ([www.morelestress.be](http://www.morelestress.be)) offers support and insights in the process of selecting and effectively using the tools in order to facilitate a dialogue about, the coping with and a positive approach to moral distress in teams and organizations.

On the Nursing Ethics Conference we would like to present an overview of the material and our hands-on experiences with implementing these tools in care organizations and care education.



### **Meaning in life of older persons: Opportunities for 'good' nursing care?**

*Susan Hupkens (1), Anja Machielse (2), Marleen Goumans (1), Peter Derkx (2)*

*(1) University of Applied Science Rotterdam, Research Centre Innovations in Care, The Netherlands*

*(2) University of Humanistic Studies Utrecht, The Netherlands*

Meaning in life is vitally important to every person. (Personal) meaning in life is the way we perceive our lives: Does it serve a purpose? Can we understand its course? Do we feel connected to others, or to something valuable? Do we believe that our lives or activities are worthwhile? Meaning in life is related to other extensive constructs like quality of life, well-being and health. It is also regarded as an important topic in ethical debates about what constitutes a 'good life'.

To find meaning in one's life can be challenging. While many elderly people perceive their lives as meaningful, others report a loss of meaning: research is mixed as to whether later life is eroding meaning or whether it is an episode of growth of meaning. Older people with a deteriorating health condition, or who are living alone, with a low socio-economic status, social isolation, or are non-religious can be at particular risk of losing meaning in their lives. In many disciplines, the subject 'meaning in life of older people' has been well covered, it is also prominent in political debates, but nursing literature about this subject is scarcely found.

According to current opinion, meaning in life is one of the principle dimensions of health. Nurses have a major role to play in health promotion. They are often in a highly favourable position to support old people in maintaining and nurturing that meaning due to their ongoing, daily interactions.

'Good care' includes the values of the patient. Nurses should be aware of the opportunities present in their work to attune their care and develop their skills to address meaning in life issues and in doing so, provide truly responsive care.

Knowledge about meaning in life may be a first step to attentiveness in this regard. This presentation is based on an integrative literature review of heterogeneous literature on this subject (Nursing Ethics, online December 2016). The review found different ways in which older people maintain or find meaning in life; in good times and bad times, through activities or by means of contemplation. Reflecting on the past or dreaming of the future.

In this presentation, I would like to discuss these different processes of finding meaning in later life and summarise them in one picture, and subsequently explore the opportunities for nurses to address this in their daily work and what implications this might have for nursing education.

## **The elective patients' choice of hospital in Finland**

*Anne Isotalo (1), Helena Leino-Kilpi (2), Riitta Suhonen (2)*

*(1) Department of Nursing Science, University of Turku, Finland; Director of Nursing, Turku University Hospital*

*(2) Department of Nursing Science, University of Turku, Finland*

In Finland, The Health Care Act (1326/2010) came into force on 1<sup>st</sup> May 2011, and it enables the patient's rights in the healthcare system. In specialized medical care, the Act entitles the patient to choose the unit of treatment in a mutual understanding with the referring physician. Freedom of choice is a moral right that is could increase patient's self-determination and their possibilities to make choices in health care.

**Aim:** The purpose of the study was to describe the freedom of choice of the hospital of elective surgical patient's as their moral and legal right in public health care in Finland. The ultimate goal of the study was to formulate the structure of the realization of elective surgical patient's choice of hospital in the public healthcare in Finland.

**Method:** The data of the study were collected by cross-sectional survey method and from the registry data. The population of the survey study consisted of adult elective surgical patients (n= 853). All public hospitals (=9) in the one catchment area were included in the study. Survey study was conducted between the April of the year 2014 and the June of the year 2015. Registry data were collected from the one catchment area and from one hospital covering the years 2014 – 2016. The data was analysed statistically.

**Results:** Based on the results, the most of elective surgical patients highly appreciated their freedom to choose the hospital, but only half of them knew that they have a legal right to make the choice of hospital at the point of referral. Only 24 percent of elective surgical patients have chosen the hospital. Those who appreciated their choice of the hospital highly and knew that they have the legal right to choose, elderly patients and patients with low educational level made the choice of the hospital more often. Based on the statistical data 3 – 7, 5 % of the patients treated were from outside of the catchments membership municipalities in the years 2014 – 2016.

Elective surgical patients appreciated the highest the quality of medical care, patient safety and availability of specialist and competency of the personnel. Patients have rated their experiences of services also high. The less important factors were standard of facilities and availability and access of services or care. Patients have searched little information on the quality and performance of public hospitals.

**Conclusion:** Healthcare professionals can support patient in taking an active role in clinical decision making. Actions should focus on patient information of their rights and actions that progress elective patients' freedom of choice in public health care. Public comparative information of hospitals performance and quality is central element of current reform toward more patient choice in healthcare. Comparative information should be publish in making possible patients to make choices.

### **Ethics and quality in nursing homes: Relatives' experiences**

*Rita Jakobsen (1), Gerd Sylvi Sellevold (1), Veslemøy Egede-Nissen (2), Venke Sørli (1)*

*(1) Lovisenberg Diaconal University College, Norway*

*(2) Oslo and Akershus University College, Norway*

Background: 71,000 people in Norway suffer from some form of dementia in 2013, of whom approximately 30,000 are in nursing homes. Several studies focus on the experiences of those who have close relatives and who are staying in a nursing home. Benefits of developing systematic collaboration practices include relief for nursing staff, less stress, and greater mutual understanding. Going through studies focusing on the experiences of nursing home patients' relatives, negative experiences are in the majority. In the present study, relatives are challenged to highlight positive experiences regarding the care of their loved ones; a slightly different perspective, in other words.

Aim: The aim of this study is to highlight relatives' experiences of their loved ones, who are suffering from dementia and staying in a nursing home, receiving proper care.

Method: The study is a part of an umbrella project called Hospice values in the care for persons with dementia, and is based on a qualitative design where data is generated through narrative interviews. The chosen method of analysis is the phenomenological-hermeneutical method for the study of lived experiences.

Participants and research context: Participants in the project were 8 relatives of persons with dementia who were living in nursing home units. Ethical considerations: the Norwegian Regional Ethics Committee (REK) and the Norwegian Social Science Data Services (NSD) approve the study.

Findings: Findings show that relatives have certain expectations as to how their loved ones ought to be met and looked after at the nursing home. The results show that in those cases where the expectations were met, the relatives' experiences were associated with engagement, inclusion and a good atmosphere. When the expectations were not met, the relatives experienced powerlessness, distrust and guilt.

Discussion: The results are discussed in light of the concepts of trust, power and asymmetry.

### **The Virtuous Regulator: Reflections on the Case of Pauline Cafferkey**

*Robert Jago (1), Ann Gallagher (2)*

*(1) Royal Holloway, University of London, UK*

*(2) University of Surrey, UK*

In December 2014 a nurse, Ms Pauline Cafferkey, returned from Sierra Leone having contracted the potentially fatal disease Ebola. It was alleged by the Nursing Midwifery Council (NMC) that whilst in a Public Health England screening area in London Heathrow Airport Ms Cafferkey allowed an incorrect temperature to be recorded on her screening form. It was also alleged that Ms Cafferkey left the screening area without reporting her true temperature and finally that she did not tell a doctor she had recently taken paracetamol. The subsequent fitness to practise panel decided in September 2016

that Ms Cafferkey was not guilty of misconduct in relation to all charges. Ms Donna Wood, another nurse travelling with Ms Cafferkey, was suspended from practising for two months having been found to have concealed Ms Cafferkey's temperature.

The case of Ms Cafferkey has highlighted a number of key issues for those interested in health care regulation. It has been asked whether the case against Ms Cafferkey should have ever been brought given her laudable actions in working in an Ebola treatment centre in Sierra Leone (Sim, 2016). On a broader level some have made reference to the 'culture of fear surrounding regulation' (Fouch, 2016) whilst the regulator themselves indicated that they had an 'overarching duty to protect the health and well being of the public' in such cases. One significant consequence would appear to be that following this case the NMC have decided not to publish details of cases ahead of disciplinary proceedings. The NMC have balanced privacy rights against press access in reaching this decision but some have argued that it does demonstrate a clear lack of transparency (Satchwell, 2016).

The authors of this paper reflect on the case of Ms Cafferkey and ask what should be expected of the regulator in circumstances such as these? Does a prima facie case demand a full investigation for fear of allegations of a 'cover up'? Has the almost universal sympathy for Ms Cafferkey's work and current medical condition clouded our view of the actions taken in December 2014? The decision by the panel to find a lack of impairment for Ms Wood's lapse in judgment whilst deciding that Ms Cafferkey's judgment was impaired by illness at the time is considered and we ask whether the regulator can and should be virtuous in circumstances such as these? If so, which virtues are indicated in this case?

### **Exposure through dialogue as an experiential learning in care relations**

Sarah Janssens (1)(2)

(1) *sTimul, Moorsele, Belgium*

(2) *Howest, Bruges, Belgium*

The research cluster Bachelor Nursing Howest University of Applied Sciences, sTimul Ethics of Care Lab, the Department of Geriatric Medicine (Ghent University Hospital) and the University Center for Nursing and Midwifery (Ghent University) have collaborated in a qualitative research project about exposure through dialogue.

Participants (eight volunteering nurses and occupational therapists) spent half an hour to an hour with a patient of choice in an open dialogue about the experiential world of the patient during their stay in the hospital. Afterwards the participants went through a reflection process by themselves, in pairs and in a focus group.

The individual, dyad and focus group interviews were recorded and transcribed. The researchers did a qualitative analysis of the dyad and focus group interviews using methods of Grounded Theory and using data and researcher triangulation.

Aim of the project was to research the possible use of this systematic exposure experience as a learning method in order to foster the appropriate care attitudes of caregivers, tuning to patients and their experiences, as a condition for person-centered care.

The results were astonishing and gave insights in the process and effects as reported by participants, features of the dialogue with the patients and important aspects of the dyad and focus group. Conclusions were:

- Dialogue can be a form of exposure.
- Through open dialogue with patients at the end of their stay in the hospital new and surprising insights arise in caretakers – even in very experienced ones, and even after a long term care relationship to the patient.
- The insights that arise are not patient-specific and neither generalised. Caregivers come to an understanding of the *need of attunement* to specific patients, rather than coming to *fixed conclusions* about the experiential world of patients and their care needs. An open dialogue with one patient has as such benefits for all patients.
- Exposure through dialogue provides caretakers with a resourcing experience in their intention and purpose of (good) care. They realize f.ex.:
  - that emotional care is part of their job as well.
  - that ‘being’ can be as valuable as ‘doing’.
  - that an orientation on tasks and problem solving can be balanced with a process orientation.
- The experience of exposure through dialogue creates an urgency in caretakers to act upon their insights and to apply them in daily care.
- Caretakers experience a need to have a mutual understanding and support with colleagues as they are proceeding towards offering more patient-oriented care.
- A high degree of transparency towards participants is recommended in applying this exposure through dialogue.
- Focus on the intention rather than on the format of the dialogue is essential. It’s not meant as a communication training.

### **Ethical aspects of nursing: Could we predict misusers in chronic non-cancer pain patients using long term opioids?**

Alena Javurkova (1), Jaroslava Raudenska (2)

(1) Department of Nursing, 2<sup>nd</sup> Faculty of Medicine, Charles University and Motol University Hospital, Prague, the Czech Republic and Department of Clinical Psychology, University Hospital FNKV, Prague, the Czech Republic

(2) Department of Nursing, 2<sup>nd</sup> Faculty of Medicine, Charles University and Motol University Hospital, Prague, the Czech Republic and Department of Clinical Psychology, Motol University Hospital, Prague, the Czech Republic

The decision to use opioids to treat chronic pain is complex and somewhat controversial. Although opioid therapy may be appropriate for some patients with chronic non-cancer pain, physicians and nurses must implement strategies to reduce opioid abuse, addiction, and diversion. The approach taken in this paper to prescribing opioids from an ethical perspective is to seek direction from each of the 4 basic bioethical principles: the principles of beneficence and nonmaleficence are grounded in the traditional Hippocratic ethic, and are accepted as guides for action by health care providers. Of more

recent origin are the principles of justice and respect for autonomy, which are linked to a drive for social justice and human rights. Each of these principles can guide physicians' decision making about opioid prescribing. Medication misuse is the intentional or unintentional use of a prescribed medication (opioids) other than as directed. Misuse can include a patient taking more pain medicine than prescribed to control otherwise inadequately controlled pain as well as abusive and addictive behaviors. Abuse refers to the intentional self-administration of a medication for non-medical purpose or the use of an illegal drug. Addiction is a primary, chronic disease defined by one or more of the following behaviors: impaired control over drug use, compulsive use, continued use despite harm, and craving. Aberrant behavior is a research term defined differently by various investigators which typically includes activities of misuse and abuse. Opioid misuse carries the risk of development of addiction, overdose, and death which require providers to balance individual patient's pain and risk levels. Patients with high risk for opioid misuse should not necessarily be denied opioid therapy but should be followed under closer supervision than those patients with lower risk estimates. Risk factors for misuse can be grouped into three categories: biological, social and psychological. Biological risk factors include family history of drug abuse and male gender. Social risk factors include poor social support and history of convictions related to drugs or driving while impaired by substances. Psychological risk factors include a personal history of substance abuse (including alcohol or tobacco), pre-adolescent history of sexual abuse, and co-morbid psychiatric illness (i.e. major depression, bipolar disorder, personality disorder). Several screening tests predict the potential for opioid misuse in patients with chronic non-malignant pain. Physicians and nurses need to ensure that their patients' pain is properly assessed and managed. Reaching optimal pain control might necessitate prescribing opioids. But the obligation of providing pain relief needs to be balanced with an equally important responsibility not to expose the patient to a risk of addiction and not to create opportunities for opioid drug diversion, trafficking, and the addiction of others. Various guidelines and practice tools are now being offered. Their use is desirable, but requires that the physician and nurses (multidisciplinary team) take into account moral values, interests, rights, and responsibilities, and hence engage in ethical analysis.

### **A concept analysis of compassion in nursing care: A Spanish, Swedish and Japanese perspective**

*Maria Jiménez Herrera (1), Monica Ragnewall (2), Annika Malmberg-Andreasson (2), Sagrario Acebedo-Urdiales (1), Mayumi Niitani (3), Chirster Axelsson (4)*

*(1) Department of Nursing, Universitat Rovira I Virgili, Tarragona, Spain*

*(2) Sahlgrenska University Hospital, Goteborg, Sweden*

*(3) Hiroshima University, Hiroshima, Japan*

*(4) Faculty of Caring Science, Work life and Social Welfare, The Center of Prehospital Research, University of Borås, Borås, Sweden*

The mean of compassion has revealed a number of attributes, objective and subjective dimensions from the givers. Compassion is an important ethical foundation for nursing. This concept have numerous perspectives and influences including cultural, cognitive, religious and humanistic. Compassionate care may not do arise when caring is reduced to technical tasks, for this reason the emotional engagement is principal for understand the meaning of the concept. Our overall aim was to

describe the phenomenon of compassion as perceived for nurses working with critical ill patients in different areas, in three different countries and cultures; Sweden, Japan and Spain.

**Aim:** The aim of this research is to describe the phenomenon of compassion in nursing among nurses from three different cultures.

**Methods:** This qualitative exploratory study was conducted with nurses selected according to their experience in working with critical ill patients in different areas. Data were collected by one focus group in each country, the number of participants in each focus group was between 8-10 nurses. Content analysis approach was used for data analysis.

**Results:** The results show the nature of compassion in the three main categories: "Perspectives of compassion", "Compassionate care" and "Ethical competence". The perspectives of compassion seems linked to the personal life world perspective more than culture and the meaning of the terms compassion and empathy are very similar for the nurses and they use this terms very often for describe feelings and actions. Compassionate care have two subcategories: "Dimensions in nursing care" and "outcomes of compassionate care". The firsts we could describe different subthemes like; "receptivity", "presence" and "connection". Some nurses feel that it's important to listen to the patients' needs because the needs have different dimensions. This is an opportunity for nurses to involve the emotional aspects in the relationship and give the ability to connect with the patient, a key component to perform person centered care. Independent of culture "the ethical competence" is essential in compassion. The nurses identified two approach to this; using the principals of bioethics and implementing ethics of care.

**Conclusions:** This study's findings show that the meaning of compassion presents not have big variation among nurses of different cultures. Compassionate care requires the development of various dimensions, regardless of where it takes place. Ethical competence is an attitude that must be developed by nurses in order to promote compassionate care and person centred care.

### **Towards transformed midwifery care for vulnerable patients**

*Priscilla Jiyane (1)*

*(1) University of Pretoria, Department of Nursing Science, South Africa*

**Introduction:** Midwifery care has become a centre for media discourse and dialogs both nationally and internationally. There is a claim that the level of care has declined into inhumane, uncaring and uncivilized midwifery care practices with resultant decrease in ethically-driven midwifery care during childbirth. Despite the above claims the participants were motivated to change the current practice themselves in order to render ethically-sound midwifery care. That was the care that intended to focus on the respect and dignity of the women who were admitted for childbirth. The objective of this study was to design a plan of action to improve professional value-driven midwifery care using a Cooperative Inquiry research approach in the selected hospital in Mpumalanga.

**Methods:** In order to attain the study objectives a Participatory Action Research design (PAR) was used. A Cooperative Inquiry research approach was followed. The type of study was a professional PAR which was conducted through a collaboration of the midwives from the department of Health and the

researcher from Nursing Education. The midwives were motivated to change their own practice to offer women-friendly midwifery care during childbirth. The population in the study was the midwives who included an operational manager, a Midwifery tutor, two advanced midwives, two Community service midwives, four registered midwives and four final year midwifery students. Purposive sampling was used to recruit the participants into the study. The data collection method used was Focus group discussions (FGD's). A thematic data analysis was used to analyse the collected data. Findings: The findings of this study were divided into four main themes. The theme of quality midwifery care which required the midwives to embrace quality midwifery care and to prevent risks, harm and the application of safer initiatives. The second theme related to the promotion of holistic well-being through the adoption of total safe midwifery care practices. Next was ensuring professional midwifery care with specific reference to skills and knowledge of midwifery practitioners and barriers to professional value-driven midwifery care. Conclusion: The midwives' adherence to ethically-driven midwifery care may result in the satisfaction of the women admitted in the Maternity ward. The midwives gained personal satisfaction from the realization of the success of the project they personally engaged in. The setting had a potential to achieve a transformed care environment that may foster ethically-sound midwifery care that intended to respect the women throughout childbirth. As such, professional ethically-driven midwifery care might be enhanced throughout midwifery care.

### **Iranian nurses perspectives about end of life care in NICU**

*Soodabe Joolaei (1), Mahboobe shali (2), Fateme Haji Babaie (2)*

*(1) Nursing Care Research Center, Iran University of Medical Sciences. Iranian Academy of Medical Sciences, Tehran, Iran*

*(2) Tehran University of Medical Sciences, Tehran, Iran*

Introduction: Neonatal intensive care unit (NICU) nurses are faced with complex clinical and ethical problems on a daily basis. The neonatal nurse provides close and continuous care to preterm and sick infants and their families. Due to this closer relationship with the newborn and his/her family, nurses deal with difficult emotional situations. It is arguable that the current view of NICU end of life care is too narrow and it have not been widely researched.

Aim: This is an exploratory qualitative study, aimed to explore the experiences of Iranian neonatal nurses in caring for dying infants and their perceptions of palliative care.

Method: 22 semi-structured interviews were conducted over 6 months in 2016 with nurses regarding their experiences of caring for infants at the end of life. The interviews were conducted using a script containing information about the participants and two guiding questions related to nurses' experiences in relation to the care of critically ill dying newborns and their families.

Results: Nurses reported that they had a very difficult time to care for end of life infants and families. Consistent themes of nurses' responses include: building relationship, using strategies to face suffering, developing communication skills, no routine education to prepare for the end of life care, trying to create the best possible experience for families.



Feeling ambivalent and helpless; protecting emotional self; providing optimal physical care to the infant; providing emotional support to parents; expressing empathy; lack of knowledge and counselling skills; and conflicting values in care

The nurses' experiences indicated their efforts to seek strategies for dealing with stress, searching how they can externalize it through crying or asking for help from other professionals when they do not feel they can meet the family's needs. In order to protect themselves from personal suffering, they developed certain protective strategies by maintaining a distant relationship with the dying infant and the family. It was easier for them to provide practical, physical care rather than psychosocial care, because of their insecurity and fear of being hurt emotionally.

Conclusion: The finding highlights the urgent need for professional and personal development in palliative care in nursing education, so that nurses may be able to recognize and confront their fear of vulnerability and the mortality of those around them, and to support parents in the bereavement process.

### **Do I care enough? The ethics of care and justice in primary nursing practice**

*Soile Juujärvi (1), Kirsi Ronkainen (1), Piia Silvennoinen (1)*

*(1) Laurea University of Applied Sciences, Finland*

Carol Gilligan claimed (1982) that there are two different moralities: the ethic of justice centred on maintaining obligation, equity and fairness through application of moral principles, rules and established standards, and the ethic of care centred on maintaining relationships through responding to needs of others and avoiding hurt. In justice reasoning, moral conflicts are solved through applying a hierarchy of rights and rules to determine which claim is the most justified. In care reasoning, moral problems are solved through considering unique characteristics of persons and situations. In the field of nursing, Gilligan's theory was initially accepted with enthusiasm, because it captured the essence of caring embedded in patient-nurse relationships and helped to understand nurses' ethical conflicts in clinical practice. Still despite its popularity, few studies have explicitly employed Gilligan's theory. Consequently, the ethic of care has been regarded as an appropriate attitude, but not as an adequate approach to guide decision-making in practice (Woods 2011).

The aim of the presentation is to contribute to the research gap by examining nurses' ethical decision-making in the context of primary nursing for geriatric patients. It is argued the ethic of care is closely aligned with the primary nursing model that enhances the nurse-patient relationship and enables more independent role for nurses in clinical decision-making. The research questions are as follows: (1) What kind of moral conflicts do primary nurses encounter and (2) how do they interpret and solve them in the context of primary nursing of geriatric patients? Six primary nurses with one physiotherapist were focus group interviewed on May 2016. The interviews were a part of the development project on a geriatric rehabilitation unit of a public hospital in southern Finland. The data were analysed by Lyons' (1983) coding scheme for moral orientations.

Preliminary results indicate that typical ethical conflicts are related to discharge process: patients' reluctance to go back home and family members' concerns about patients' coping at home. Care and

justice are intertwined in primary nurses' ethical decision making. Patients' frailty and vulnerability calls for care-based considerations that are framed by official admission standards for institutional care invoking justice-based considerations. Primary nurses have to work out the ethical solution balancing care and justice aspects. Furthermore, patients who remain passive recipients of care instead of engaging in rehabilitation process pose big ethical challenges to primary nurses. As a conclusion, the primary nursing model enables gathering contextual knowledge that is utilised in multi-professional decision-making and emphasises nurses' independent role in caring process. Shortcomings of the primary nursing model /the ethic of care are discussed in the context of the current elderly care in Finland.

References:

- Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Cambridge: Harvard University Press.
- Lyons, N. P. (1983). Two perspectives: on self, relationship and morality. *Harvard Educational Review*, 53, 125-145.
- Woods, M. (2011). An ethic of care in nursing: past, present and future considerations. *Ethics and Social Welfare*, 5(2), 266-276.

### **Ethical deliberation and co-creation of good care**

#### **Mariël Kanne (1)**

(1) *Utrecht University of Applied Sciences, Utrecht, The Netherlands*

Without co-creation, there can't be good care. This statement is based on various theories from different disciplines: Tronto's ethic of care, Ricœur's philosophy of the self, Sennett's ideas on craftsmanship, Schön's theory about the reflective practitioner, Wierdsma's view on co-creation of change in organizations and Kunneman's thoughts on normative professionalization and mode three knowledge.

But in the practice of healthcare and social care, co-creation of good care often is problematic. Because everyone who is involved in a situation where care is needed can give a different answer to the question: what is good care for this person in this situation? According to all the above mentioned theories, everyone involved in the ongoing process of care should sit at the table when it comes to making decisions about a just distribution of care and care responsibilities. Because both knowledge and experiences, as well as possibilities and competencies of every stakeholder should be taken into account. This implies that organizations and institutions should create a 'political or moral space' and 'a third place' (Tronto, 1993; 2013), which can also be called 'a place of difficulty' or an 'ethical space' (Wierdsma, 1999) Here all persons involved in a specific situation/in a concrete context can reflect and negotiate to find answers to the question 'what is the good and the right thing to do?'. The result of this 'euboulia' or 'good deliberation' (Ricœur, 1990) is that everyone, each in his/her role, can be a responsible actor.

The introduction of 'moral case deliberation' (MCD) in many Dutch organizations for health care and social care could be seen as a practical concretion of the theoretical concept of such a space or place for ethical reflection and deliberation. MCD consists of a multidisciplinary (team)meeting on a concrete

moral question arising in professional practices, guided by a (trained) facilitator who follows a specific method to structure the dialogue.

Research has been done into the effects of MCD with regard to co-creation of good care. Some remarkable conclusions of this research:

- Because inequality of power is inherent in care relations, care is never without conflict and this becomes apparent in MCD: participants learn to see a problematic situation from a different point of view and thus become aware of the complexity of the context in which they act. Although this makes their work more difficult, most participants appreciate the fact that they see new perspectives and alternatives for action.
- Participants often are affected by a feeling of powerlessness or think they are incapable to change situations. This is expressed in emotions like anger, frustration or fear. But when there is explicit attention for the different positions of persons involved in the process of care and inherent power-differences, participants get to see their own possibilities. This empowers them and provides them with arguments they need to be accountable and responsible professionals.
- MCD contributes to the 'ethics work' (Banks, 2013) that enables nurses and social workers to develop their personal and professional identity.

### **A conceptual model of patients' loneliness experiences in professional caring relationships and associated factors**

*Liisa Karhe (1), Marja Kaunonen (2), Anna-Maija Koivisto (3)*

*(1) Tampere University Hospital, Finland*

*(2) University of Tampere, Pirkanmaa Hospital District, Finland*

*(3) University of Tampere, Finland*

Background: Patients may be lonely in their relationships, including those with nurses and doctors. Loneliness in relation to health care professionals is a new application of the loneliness concept that provides a useful starting point for ethical reflection and for the development of patient-centered care and research.

Purpose: The purpose of the presentation is to describe the development and the contents of the conceptual model of patients' experiences of loneliness in professional caring relationships.

Methods: The building of the conceptual model followed Norris's concept clarification phases. The first phase included the evolutionary concept analysis, which looked at the nature of patient loneliness through a variety of disciplines. The second phase described the conceptual meaning and significance of patient loneliness in the professional care context. The empirical analyses based on the conceptual examination included a qualitative thematic interview with breast cancer and cardiac surgery patients (N=13). The third phase included the operationalization of concept. The qualitative content analysis results were applied in the development of Caring Loneliness Scale (CARLOS) for the measurement. A postal questionnaire study was conducted with it to collect validation data among breast cancer and cardiac surgery patients (n=250) six months after surgery. The CARLOS scale was then further piloted

with an even larger sample (N= 406). This included an examination of how sociodemographic and health-related background factors were associated with patient experiences of loneliness in professional caring relationships. The conceptual model was synthesis of the results describing the concept of professional caring loneliness and the key concepts, contributing and alleviating factors, consequences and associated factors.

Results: The conceptual model of professional caring loneliness describes what loneliness means for patient and what are the contributing and alleviating factors, consequences and associated factors. Professional caring loneliness appeared to the patients as being outsiders, and not encountered as human beings. Loneliness also revealed in a way that the patients not receiving help and understanding and not having the opportunity to share their experiences, feelings and knowledge with professional caring people. Loneliness meant for patients not being respected, not being heard or taken seriously. They felt also that professional caring people were distant and inaccessible. The patients described their loneliness experience as traumatic and such that they did not wish anyone else to have to experience the same.

The patients reported their loneliness experiences causing them suffering, uncertainty, mistrust and insecurity, but also negative feelings, but annoyed patients also found themselves new resources to survive on. The professional caring loneliness was associated with patients' perceived health, recovery and psychological distress.

Conclusion: Professional caring loneliness is humanly and ethically sound but also socially significant issue, because the health care task is not to increase patient loneliness. Each professional caring people can affect the prevention of loneliness with human and caring attitude and with responsible professional behaviors and activities, but also the organization-driven factors and education can support and allows for the prevention of loneliness.

### **Responsibility as an ethical challenge in nursing practice and the importance of defining the body of knowledge**

*Dag Karterud (1), Dagfinn Nåden (1)*

*(1) Oslo and Akershus University of Applied Sciences, Norway*

“How to be responsible as a nurse practitioner, has always been an important subject matter in nursing education and ethics.

But, it is not self-evident to know what to be responsible for as a nurse. Ethics discusses what may be right or wrong in certain contexts or situations. Therefore, it is important to reflect some issues according to the boundaries of the Nursing profession. How do nurses confine and discipline themselves when facing all kind of needs, sorrows, and sufferings, and still recognise themselves as competent and considerate? How do they deal with all sorts of expectations for instance the society, the doctors, and the relatives? If there are no limits what so ever, how do the different contexts within healthcare influence the sense of responsibility within the profession itself?

Nursing Science implies to guide the Nursing profession and Nursing Practice to be morally obliged to the legitimate needs and demands of the patients, which are to be cared for by nurses. But, there have

to be some boundaries according to practical tasks and according to the ethical demands from the patients and the health care system, unless the Profession might become omnipotent, and not 'professional' in considering the overall perspectives consider the patients' needs for nursing care.

Thus, this paper will discuss The Nursing Science's body of knowledge in connection to the ethical concept of responsibility to inform and benefit Nursing Practice."

### **Patient reported outcomes of quality of end-of-life care in long term care settings**

*Tara Kearns (1), Nicola Cornally (1)(2), William Molloy (1)*

*(1) Centre for Gerontology and Rehabilitation, University College Cork, Ireland*

*(2) Department of Nursing and Midwifery, University College Cork, Ireland*

By 2050, there will be 392 million people worldwide aged 80 years and over; more than three times the current number (1). In developed countries, this demographic transition is underpinned by an epidemiological transition from high infant and maternal mortality, and high infectious disease rates, to low premature mortality and a predominance of chronic, non-communicable disease (2). In congruence with population ageing, societies are ageing. Family size is decreasing and traditional, family-based options for end-of-life care are becoming less common (3). People are dying later in life, increasingly from chronic disease, and more frequently in long-term care than at home (4). It is estimated that as many as 60% of patients in LTC have cognitive impairment or dementia, many of whom do not have a formal diagnosis (5-8).

The majority of the research to-date in evaluating end-of-life care has focused on patients with cancer in its associated care settings. While many of the physical symptoms experienced by cancer patients are common to other chronic disease populations, the patient experience at end-of-life is necessarily different. Patients with non-malignant disease experience more burdensome symptoms in the last year of life than those suffering from cancer, not only because of the greater number of symptoms, but also because of the more protracted trajectory of decline in chronic conditions (9,10).

Currently, the evidence base for measuring quality of end-of-life care is founded on the cancer-acute care paradigm. Development of the evidence base necessitates measurement of the patient experience beyond these confines. Patient reported outcomes are critical to understanding how end-of-life care services and practices affect patients' health and end-of-life experience. Patient reported outcome measures describe the quality of care from the patient's perspective and add balance to existing clinical or proxy-derived knowledge on the quality of care and services provided.

There is a paucity of studies that evaluate quality of end-of-life care for patients with chronic disease outside the established cancer-acute care paradigm, particularly for those in long-term care. Additionally, the absence of any patient reported outcome measures for patients with cognitive impairment/dementia precludes measurement of quality of end-of-life care for the majority of residents in long-term care.

In order to address this gap, this PhD study aims to develop and psychometrically evaluate a patient-reported outcome measure of quality of end-of-life care for use in long-term care settings, with residents with varying levels of cognitive ability. The preliminary results from interviews with patients

in long-term care settings, discussing their perspectives and concerns regarding quality of end-of-life care show a discrepancy with the domains of care traditionally used in patient reported outcome measures of quality of end-of-life care. This highlights the need for the development and use of a distinct set of patient-reported outcomes for this population. Additionally, a particular set of methodological and ethical challenges in conducting end-of-life care research with this population was identified.

### **An integrative literature review of moral distress amongst nurses in acute hospital adult wards**

***Gerardine Kennedy (1)***

*(1) University College Cork, Ireland*

Background: Moral distress has been described amongst nurses and other healthcare workers and arises when the nurse cannot follow the morally right course of action due to institutional or professional constraints. It is associated with negative effects on nurses and on patient care. While moral distress has been researched amongst nurses, much of this has focused on staff in specialist and critical care environments. It would be timely to identify general nurses' experiences of moral distress in the increasingly challenging ward environment where reduced staffing, increased patient acuity and dependency with faster turnover of patients is the norm. These pressures compete with the professional values of care centred on patient dignity, respect, advocacy and professional engagement with patients who are vulnerable and are related to suboptimal care and standards in the acute hospital ward setting. Despite numerous recruitment drives thousands of positions in Ireland remain unfilled in nursing intensifying the need to address these issues.

Rationale: There is a gap in the research literature on the impact of moral distress on nurses in general acute care settings and implications for patient care and staff retention. This integrative literature review brings together qualitative and quantitative literature to provide a comprehensive overview of moral distress in this context and identifies the need and direction for further research in the acute hospital ward setting.

Aim: The research questions guiding this literature review are: 1) How prevalent is moral distress amongst nurses on general wards in acute hospital environments? 2) What are the main causes of moral distress for nurses in this setting? 3) How does moral distress impact on patient care? 4) How does moral distress impact on nurses personally and professionally?

Plan: Key findings indicate a dearth of quantitative studies at national level of moral distress amongst nurses in acute hospital ward settings, moral distress can be consistently described when based on a validated moral distress scale and moral distress is related to mostly negative effects on nurses and on patient care. These findings justify and provide the focus for a quantitative study of the moral distress of nurses in acute hospital wards in Ireland to help address this issue.

## **Galen, Virtues and Good Care**

Carla Kessler (1)

(1) *Utrecht University, The Netherlands*

In twentieth and twenty-first century virtue ethics became increasingly popular in the field of bioethics. Especially in medical professional ethics we meet a lot of philosophers engaging in virtue ethics<sup>1</sup>. As virtue ethics originally stems from ancient Greek philosophy, for a large part from Aristotle, I want to have a close look at one of the founding fathers of Western medicine, Galen of Pergamum (129-216/7).

Galen was a famous physician at the time: he was not only known for his remarkable cure of patients and his extensive knowledge, but also for his demonstrations of anatomy, performed on living animals. Evidence-based medicine was very important to Galen and, therefore, he frequently wrote about this topic. Fortunately, he left us an impressive body of literature; his preserved writings alone amount to ten percent of all surviving literature in Greek prior to AD 350.

Recently Galen has been rediscovered in light of our own medical-ethical questions. He argued that a good doctor also ought to be a philosopher, trained in ethics and logic. The questions I would like to answer and discuss in the lecture are 'do virtues play a role in Galen's work?' and 'can we find some kind of *phronèsis* – practical wisdom – as key notion in his philosophy on good care?'

---

<sup>1</sup>See for instance Rosalind Hurtshouse's 'Virtue Theory and Abortion' (1997), Philippa Foot's 'Euthanasia' (1977), Edmund Pellegrino's 'Toward a Virtue-Based Normative Ethics for the Health Professions' (1995), and Matthew McCabe's 'Virtue in the Clinic' (2014), amongst others.

## **Ethical problems that health care professionals meet in care of communicable disease patients**

Mia Ketonen (1), Helena Leino-Kilpi (2)

(1) *University of Turku, Department of Nursing Science, Finland*

(2) *Department of Nursing Science, University of Turku and Nurse Director, Turku University Hospital, Finland*

Communicable diseases are in major role in people's well-being all around the world. Patients who are suspected to have or have an infection caused by a communicable disease are being cared in health care. Caring these patients raise ethical questions that have an impact to patients' and health care personnel's well-being.

The purpose of the literature review was to find out and describe what kind of an ethical problems health care professionals meet in their work caring for patients with communicable disease. The purpose was also to find out in what areas ethical problems occur.

The method of the study is a literature review. Data was collected from PubMed, CINAHL, Medica, Cochrane, Web of Science Core Collection and Scopus databases in August 2015. Also manual search was performed. Search terms used were: health care professional, communicable disease and ethic. Inclusion criteria were peer-reviewed scientific papers where the main focus was on care of communicable disease patients. At the end sixteen articles were selected and included in the review.

Ethical problems identified from the data was picked up one by one. All information related to each identified ethical problem was gathered together and analysed.

Ethical problems concerning care of communicable disease patients are related in patients right to be informed, confidentiality, right to access health care and right to proper and equal health care where they are treated respectfully and appropriately by health care personnel. Ethical problems raise in situations where patients' rights are not fulfilled or they are in conflict with health care professionals' or other peoples' rights. There exists an ethical and unsolved conflict between health care professionals' duty to care communicable disease patients and patients' right to access health care and good quality health care. Ethical problems that health care professionals meet when caring communicable disease patients appear in micro, macho, meso and macro levels.

Unfulfilled patients' rights and conflict between patients' and other peoples' rights generates ethical problems in care of communicable disease patients. By disclosing the ethical problems, we can help health care professionals to notice, handle and solve ethical problems they experience in their work. In the future the concept "Duty to care" requires a clarified definition

### **Advance care planning for the chronically ill: An exploration of relational autonomy**

*Tieghan Killackey (1), Elizabeth Peter (1), Jane MacIver (1)(2), Shan Mohammed (1)*

*(1) Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, Canada*

*(2) University Health Network, Toronto, Canada*

Advance care planning (ACP) is an iterative process whereby individuals reflect on and articulate personal values and goals, and identify a substitute decision maker in order to guide future medical treatment or end-of-life care. This process has been regarded within healthcare systems nationally and internationally as a beacon of respect for individual patient autonomy and a rejection of medical paternalism. ACP is a complex social practice that exists at the intersection of law, ethics, politics, and healthcare, with the goal of preserving individual autonomy beyond the point at which personal capacity may be lost.

The practice of ACP was borne out of the strong neoliberal ideologies of Western society, which emphasize individualism, self-determination and the protection of personal freedom and rights. A significant amount of research has identified that ACP is considered important to healthcare providers as well as patients and their families, and is recommended to take place early and often with patients who are chronically ill. However, despite numerous campaigns and interventions that seek to implement this practice, ACP has failed to become consistently adopted by the general public or by the acutely or chronically ill, and participation rates remain low even 25 years after its original legislative introduction.

This presentation will demonstrate how the current biomedical model of healthcare, which dictates an individualistic approach to autonomy, does not sufficiently capture the relational, social and emotional components of the complex decision-making processes involved in ACP. Critical social theory will be used to explore why ACP has failed to achieve its intended goals within Westernized healthcare systems. Additionally, the individualistic underpinnings of ACP practices will be problematized, and a relational conception of autonomy will be presented as a more suitable



alternative for understanding this practice. This presentation will explore how the agentic skills necessary for individuals to successfully participate in ACP are developed through relational and social processes, and therefore that a relational conception of autonomy is necessary when considering patients who are making challenging medical decisions regarding future care wishes. Finally, using the framework of relational autonomy, the opportunities for chronically ill patients to develop and express autonomy through the ACP process within current healthcare contexts will be examined.

### **Caring through technology: Challenges and opportunities for a good patienthood**

Asle H. Kiran (1)

*(1) Norwegian University for Science and Technology, Trondheim, Norway*

Ethics of technology typically concerns itself with the normative challenges regarding the design, implementation and regulation of technology. Only indirectly will it deal with challenges seen from a user perspective. For instance, the main normative question for a care receiver expected to use an assistive technology is not whether it at all should be made part of the healthcare services or what its socio-economic consequences are, rather it is: “how can this technology be adapted to my life?” For some persons, having to use a medicine dispenser rather than being helped by family or home care services might be an intimidating task, epitomizing a technical invasion of their daily lives. However, others might welcome the extrication and sense of freedom it can provide. Despite approaching the technology quite contrarily, both groups face the task of making the technology an integral part of their patienthood. This is the starting point of what is fast becoming the norm in home care: living a technologized patienthood.

Technologized patienthood has some similarities to what Heidegger (1927) called thrownness: when we are born, we find ourselves always already within a world that is made up of various (social, technical, etc.) structures of meaning. In order to achieve anything in this world (from mere communication to self-realization) we need to relate to the web of meanings that exist around us. These structures define us as who we are, but more importantly, they also constitute the possibilities we have to become; the potential to attain a given identity and personhood (Kiran 2012).

For a user in a home care setting, the situation is of a comparable thrownness: Because of a certain illness or a frailty, the care receiver is expected – by family, the national health care system, or by an insurance company, to relate to and use a given piece of assistive health care technology. How the care receiver deals with this situation, however, is not just about alleviating concrete tasks; the manner in which a technology is approached and put to use co-define how a care receiver can realize his or her own potential. Seen from this perspective, the technology harbors an ambiguity: it disciplines; “demanding” a certain technical regime to be respected, but it also presents possibilities to become a certain type of care receiver (Kiran, Oudshoorn and Verbeek 2015). By opening up such possibilities, assistive health care technologies urges a re-thinking of what a good patienthood might imply.

Dealing with assistive health care technologies through this existential approach rather than a functional approach can seem daunting, but it is a domain of care in which an ethicist can contribute. Not by doing ethics of technology, but by doing ethics with technology (Kiran 2017). In this talk, I shall

first outline what an ethics with technology will imply for (technologized) home care, before I turn to what this implies for service and policy innovation in home care planning.

**Doing participatory action research and moving ethics in the hospital arena: A three-level-model: education, companionship and open space**

Helen Kohlen (1)

*(1) University of Vallendar, Germany*

When bioethics moved into the hospital setting in the 1980s (Rothman 2003), clinical ethicists and members of hospital ethics committees based clinical case analysis on a principle-based approach. The four principles approach by Beauchamp and Childress (1983) is still the favoured model when doing ethical case consultation.

As my field study in Germany (Kohlen 2009) reveals, the use of principle-based ethics with a focus on autonomy marginalizes or dismisses issues of care. Questions of responsibility and competence are not brought to a head.

Due to these findings a participatory action research project was developed (2010) with the intention to move ethics in the organization by including a care ethical perspective. Seven German (Berlin) hospitals are participating in the project. All of them are Lutheran ones and have the same head organisation.

The circling processes of problem definition, planning strategies of problem-solving, learning and changing perspectives as well as practices is moving has brought about a model that addresses the move of ethics on three levels: education, companionship and open space. Interactivity and a lively network of learning communities has been key in the whole process. Moreover, conflicts and unequal power relations are addressed and seen as matters that belong to ethical deliberations.

In this paper I will present the action research project in detail, its current findings and focus on the on-going processes of (self-) evaluation.

**Educating professional pride to nursing-students?**

Jos Kole (1)

*(1) Radboud University Medical Center, IQ healthcare- Ethics of Healthcare Nijmegen, The Netherlands*

It is more and more accepted that a virtue ethical approach to the moral education of nursing-student may be fruitful or even necessary. Yet, to consider 'professional pride' as one of the character traits that nurses should cultivate in order to be(come) good nurses, is contestable, to say the least. After all, isn't pride a vice?

Nevertheless, the claim of this paper is that we should develop our curricula (and the practice of nursing in general) in such a way that students will become nurses with professional pride. In order to

argue for this claim, I will explain how we may understand the concept of 'professional pride', why it may seem a vice at first sight but is a virtue nonetheless. Then I will argue why professional pride is a character trait that nurses (and nursing-students) should cultivate, nowadays, as antidote to divers factors that undermine nurses' possibilities to strive for the 'internal goals' of their practice. Cultivating professional pride is necessary to uphold the moral quality of the practice of nursing in current circumstance in healthcare in Western countries. And the best way to cultivate this virtue is to start with educating it to our nursing students. I will conclude with some practical consequences for nursing education. Of course, the central claim of this papers is contestable. Therefore, I welcome a discussion with the participants of the conference of the pro's and con's of my claim.

#### References

- Armstrong, A. E. (2007). *Nursing ethics: a virtue-based approach*. Houndmills, Basingstoke, Hampshire ; New York: Palgrave.
- Banks, S., & Gallagher, A. (2009). *Ethics in Professional Life. Virtues for Health and Social Care*. Palgrave Macmillan.
- Brody, J. K. (1988). Virtue Ethics, Caring, and Nursing. *Research and Theory for Nursing Practice*, 2(2), 87–96.
- Heyl, B. (2012). *De beroepstrots van verpleegkundigen en verzorgenden. Pleidooi voor een sterke beroepsorganisatie*. Den Haag: Stichting Beroepseer.
- Jansen, T., Brink, G. V. D., & Kole, J. (eds.). (2010). *Professional Pride. A Powerful Force*. Amsterdam: Intl Specialized Book Service Inc / Boom.
- Jubilee Centre. (2015). *Statement on Character, Virtue and Practical Wisdom in Professional Practice*. Birmingham: The Jubilee Centre for Character and Virtues. Downloaded from [http://www.jubileecentre.ac.uk/userfiles/jubileecentre/pdf/Statement\\_Character\\_Virtue\\_Practical\\_Wisdom\\_Professional\\_Practice.pdf](http://www.jubileecentre.ac.uk/userfiles/jubileecentre/pdf/Statement_Character_Virtue_Practical_Wisdom_Professional_Practice.pdf)
- Sellman, D., & Cribb, A. (2011). *What Makes a Good Nurse: Why the Virtues Are Important for Nurses*. London/Philadelphia: Jessica Kingsley Publishers.

#### Measuring respect in the care of older patients

*Jaana Koskenniemi (1), Helena Leino-Kilpi (1), Riitta Suhonen (1)*

*(1) University of Turku, Department of Nursing Science, Finland*

Background: Respect is a base for high quality nursing care. Patients have a right to be cared with respect and nurses have a duty to give high-quality nursing care. However, respect has seldom been a topic of nursing studies. Especially, empirical studies investigating older patients' perceptions of being respected by nurses are rare.

Aim: The aim of this study was to develop and test an instrument measuring older patients' views of being respected by nurses.

Methods: The instrument measuring respect was developed inductively based on the results of two interview studies and literature. Altogether 30 older patients and one of their next of kin (n=30, N=60) described how respect manifested in nurses' being and doing in older patient-nurse relationship. The positively scored 20-item instrument using a VAS-scale (0-100) was developed using two expert panels

of researchers of ethics, and piloted in a sample of 30 older patient in one hospital. The newly developed instrument was empirically tested by interviewing individually older patients (N=196) cared for in two hospitals in South-West Finland. Descriptive statistics and psychometrics, such as Cronbach's alpha coefficients and factor analysis were computed. The CBI-Respectful Deference to Others was used to evaluate construct validity of the newly developed instrument.

Results: Older patients were mainly women (67 %) with an average age of 82 years. The 20-item VAS-scaled instrument has five sub-scales representing sub-concepts of respect with high internal consistency for each sub-scales and the entire scale. Correlations between the newly developed instrument and the CBI-Respectful Deference to Others were high. More detailed results will be reported in the conference.

Conclusion: The instrument proved to be promising in assessing respect in the care of older people, one aspect of ethical quality of nursing care demonstrated in the patient-nurse relationship. The results will help nurses to reflect on respect manifested in their being and doing when caring older patients. Further, findings could be used for developing interventions to support and enhance respect in nursing care.

### **Strong evaluations: Relevant or not as grounds for remaining in the nursing profession?**

Margareth Kristoffersen (1), Febe Friberg (1)

(1) *University of Stavanger, Stavanger, Norway*

Background: Why nurses remain in the profession is an important question because nursing literature has documented a global shortage of nurses and there is worldwide concern about this, implying a dramatic increase in the need for nurses with the demand expected to be greater than the growth in the supply. Although the question is also complex, the presentation will propose that strong values can be grounds for remaining, meaning nurses evaluate the qualitative worth of their different desires and distinguish between senses of what is a good life.

Aim: The presentation aims to consider the relevance of strong evaluations for remaining in the nursing profession, i.e. it considers whether strong evaluations are relevant or not as possible grounds for understanding what is of significance for nurses to remain. The Canadian philosopher Charles Taylor and specifically his understanding of the concept of strong evaluations will be used in the analysis.

Method: Based in a hermeneutic approach, different theoretical perspectives will be merged together with empirical data from a former study that consisted of qualitative interviews and qualitative follow-up interviews with 13 nurses. The research context was the primary and secondary somatic and psychiatric health service, inside as well as outside institutions.

Findings: Remaining in the nursing profession can be understood as revolving around being a strong evaluator. This will be concretized in issues of being aware of different incidents in life and having capacities as a nurse. The nurses gave more concrete descriptions of the experiences that inspired their decision to enter nursing and that influenced their professionalism.

Discussion: The relevance of strong evaluations for remaining in the nursing profession is discussed in relation to how nurses have shaped themselves by reflecting on what is of significance in their lives.

They saw themselves against a background of distinctions between things. Consequently, remaining can be understood as an expression of a life-choice. It incorporates what nurses evaluated as strong values or the categorical or unconditional worth of different desires and values used to morally justify the priority of remaining in the nursing profession. This priority can then be classified as based on qualitative discriminations because it is evaluated as something higher, more virtuous and fulfilling, noble and profound than not remaining. However, being a strong evaluator cannot be seen as the casual condition for remaining.

Conclusion: Remaining in the nursing profession is obviously not a contingent matter, rather it is a matter concerned with nurses' awareness of how a life-choice impacts on whether they remain or not. Thus, nurses may need to articulate and reflect on their priorities for remaining. For ethical education in nursing and care it might therefore be important to bring this issue into focus and challenge nurses in relation to questions such as what is of significance in their lives and with reference to the kind of beings they are.

### **A strengths based approach in a study of facilitated reminiscence**

*Assumpta Ryan (1), Brendan Bunting (1), Maurice Mulvenna (1), Kevin Curran (1), **Elizabeth Laird** (1), Claire McCauley (1), Aideen Gibson (1), Finola Ferry (1), Raymond Bond (1)*

*(1) School of Nursing, Ulster University, Northern Ireland*

Aim: To highlight the ethical issues that we encountered and addressed in a dyad focused reminiscence study

Background: Without due attention, ageism and dementia-ism on the part of researchers can contribute to the malignant social psychology experienced by older adults living with dementia.

Strengths based approach: Our study, underpinned by values of personhood and empowerment focused on the strengths of older adults in the development of an i-Pad App to support individual specific reminiscence. In a joint approach, adults living with dementia and their family carers were considered dyads, with both having an equally active role throughout the entire research process. Collaborators in the planning of the study encompassed a lead dyad, reminiscence experts, and professionals employed in statutory memory services and the Alzheimer's Society.

Three phased study: Phase 1: The co-creation and testing of a reminiscence i-Pad App and user friendly information by a User Development Group comprising a sample of six dyads. Phase 2: A sample of 60 participants (30 dyads) recruited to a quasi-experimental study received guidance about facilitating reminiscence and the collection of memorabilia from trainers of the Reminiscence Network Northern Ireland, and training from an IT assistant in the use of the App to reminisce. Following this, the participants used the system in their own homes for three months. Data were collected pre-intervention and then at mid- and end- points during the intervention period. Outcome measures examined the impact of reminiscence on mutuality, wellbeing, quality of life and quality of the care-giving relationship. Phase 3: In a qualitative study, interviews were conducted with a sample of participants to explore their views and experience of using the reminiscence App.

Ethical issues: Each phase of the study presented the research team with ethical issues, and these will form the basis for the presentation. Ethical issues included:

1. Embracing inclusive ways in planning the study
2. Developing sensitive use of language and rhetoric in verbal and written communications
3. Utilising a co-creation model in the development and testing of the App and study documentation, and doing so in such a way that met the requirements of the ethics committees.
4. Developing recruitment procedures that were appropriate, inclusive and not paternalistic.
5. Managing the different needs of adults living with dementia and their carers in the context of a dyad focused research study.
6. Facilitating informed consent in all stages of the study and in the presence of some aspects of cognitive decline.
7. Observing a reappraisal of past painful memories.
8. Conducting interviews involving sensitive issues
9. Responding to disclosures about past events in situations where the adult living with dementia and the carer have different views on how to proceed.

Conclusion: This study highlights how potential ethical challenges in a research study involving older adults living with dementia can be overcome through user engagement and reasonable adjustments. Such measures have facilitated the involvement of older adults living with dementia and their carers in the co-creation and utilisation of technology to positively impact quality of life and relationship.

### **Dealing with mental illness within families: Why finding balance in social networks requires moral work**

Elleke Landeweer (1)

(1) *Centre for Medical Ethics, University of Oslo, Norway*

Background: Recent studies emphasize the importance of social networks for persons with mental ill health to prevent crises and foster recovery processes. Their support can make a difference. Nevertheless, supporting a relative or close friend to deal with mental illness is not always an easy quest and sometimes jeopardize relationships. In this presentation it is argued that involvement of important others in the care for an ill relative requires *moral work*. The care and support within social networks demands balancing between various moral responsibilities and expectations.

Methodology: Two cases will be presented that illustrate different coping strategies of the people closely involved. Data springs from interviews conducted with the members of the social networks related to the two cases. A theoretical framework of family care ethics is used to deepen our understanding into the moral challenges within social networks.

Findings: Both cases illuminate moral complexities in different ways. Analysis of both cases illustrate that in both stories important others as well as the person with mental ill health experience challenges in how to best balance the different moral responsibilities and expectations. Both express different moral responses that spring from reasons for love. While in one case the network choose to involve a

wider circle of friends, in the other case, borderlines are drawn and the loved ones tried to loosen their involvement in the life of the person with mental ill health.

Discussion: Moral work within social networks relates to reaching out to others as well setting boundaries within a context where a moral compass is not evident or available. Professionals could support important others in their moral work by inviting them to talk about their moral dilemmas and help them find solutions that correspond to the values and norms within their social network.

### **Holistic care interventions for older people: A scoping review**

*Carlos **Laranjeira** (1), Isabel Renaud (1), Paula Ponce Leão (2)*

*(1) Universidade Católica Portuguesa, Instituto de Bioética, Porto, Portugal*

*(2) CECH/ Universidade de Coimbra, Coimbra, Portugal*

Background: The concept of holistic care in today's nursing helps to enhance the total well-being of the person who is under medical care or treatment. Portraying the human being only by his present needs is insufficient. Every individual is unique and should be cared for as an entity comprising of body, soul and spirit. The purpose of this scoping review was to map the literature on holistic care approach for older people in healthcare settings.

Methods: Searches of three electronic databases were conducted to identify studies published over the last 10 years. Eligible studies explored perceptions or interventions of holistic care in older people. A narrative approach to synthesizing and mapping the literature was used.

Results: Of 8,215 records, 248 studies were retrieved and 18 studies were included in the review. Twelve of these articles were narrative review articles. The remaining studies included two randomized control trial, two prospective study and two qualitative research papers.

Conclusions: While no unifying holistic care model was found, a consensus among frameworks of different disciplines suggest that three components of person-centered care for older people have been consistently recognized as critical to the process. Appropriate case management, effective communication and positive interactions have been considered across multiple areas of clinical practice although rarely through empirical studies. A deeper understanding of the key behaviors and attitudes that lead to improved older person-reported outcomes through holistic care is essential.

### **Use of innovative technologies with adults aged of 65 years old and more: Ethical issues for homecare and nursing homes' care.**

*Thomas Kampel (1), Christine Cohen (1), Pia Coppex (1), Delphine Roulet Schwab (1), **Virginie Le Fort** (1)*

*(1) University of Applied Sciences of Western Switzerland, Institute and Nursing School La Source, Lausanne, Switzerland*

Background: For a long time technologies has been used in nursing care. Since the democratization of mobile devices and computers, the development and marketing of technologies designed for elderly

people are exponentials – especially their use for health. Their availability encourage home care and nursing homes working with elderly people to question which technology and interventions to implement.

Ethical issues: The use of technology in providing healthcare and support to elderly people needs an in-depth ethical questioning. It should cover both the principle of autonomy: “Do we really know what the elderly people want?” Additionally, it should consider the principles those of beneficence and non-maleficence: " Who’s good interest are we developing those technologies?" and "Who’s good may the development of this technology hinder?" It also matters to determine if the considered technology (1):

- Allows to respond to the needs and expectations of the elderly people, whether they be in situations of dependency or not;
- Respects the right of all people involved in self-determination regarding free and informed consent, privacy protection and security;
- Improves quality of healthcare delivery ;
- Improves quality of life for the healthcare professionals involved.

Practical questions: Before the technology is used, the healthcare professionals should try to respond to the following questions (2) :

- Has the device been presented to the person?
- Does the person understand what the device will do?
- Have all the alternatives to the device been completely explained to the person?
- Has the person agreed to the use of the device?
- Did the person’s family caregivers participate in this exchange?
- What are the risks and tensions created by the use of the device for all people involved?
- Has the implementation of the device been organized?
- How will its effectiveness be assessed at short, middle, and long term?
- What is the strategy to remove the device?
- What is the protocol for the use of the device for all people involved?
- Are there people capable of responding in case of an emergency or difficulty while using the device?

Institutional assessment: When an institution wishes to introduce a technology, it should be assessed on six dimensions: the technical aspect (sturdiness, reliability, maintenance), the direct link between the technology and the user (ergonomics), the inputs in term of health (therapeutic non-medicinal possibilities), the social service given (improvement or creation of services), the financial dimension (costs and benefits), and the legal and ethical dimensions (rights, duties and responsibilities) (3-6).

Conclusion: The healthcare professionals should be aware that the utilization of technologies may generate tensions between several biomedical ethics principles. This aims to provide suggested lines of questioning for the heads of institutions and for the teams involved in healthcare and support for elderly people living at home or in nursing homes.

References



- Rüegger H, Schwab Roulet D, Eggert N. Aspect éthiques liés à l'utilisation des technologies d'assistance dans les institutions de soins de longue durée (EMS). Bern: CURAVIVA Suisse, 2016.
- Kampel T, Cohen C, Verloo H. Positionnement éthique face à la gérontechnologie. *La gazette médicale*. 2016(4):2-3.
- Eccles A, Gilhooly Ma, Damodaran L. Ethical considerations around the use of information and communication technologies with older people. *Gerontechnology*. 2010;9(2):83.
- Normie L, SavageAVAGE R, Mortenson WB. The ethics of gerontechnology: From intervention study to implementation in practice. *Gerontechnology*. 2010;9(2):142.
- Rialle V. Technologie et maladie d'Alzheimer. *Soins Gerontologie*. 2008;74:26-8.
- van Hoof J, Kort HSM, Markopoulos P, Soede M. Ambient intelligence, ethics and privacy. *Gerontechnology*. 2007;6(3):155-63.

### **Dealing with existential suffering of patients with severe persistent mental illness: Experiences of psychiatric nurses in Flanders (Belgium)**

*Joke Lemiengre (1), Christoph Moonen (2), Chris Gastmans (3)*

*(1) University College Leuven-Limburg; sTimul Care-Ethics Lab (Lubbeek), Belgium*

*(2) PC Guislain, Ghent, Belgium*

*(3) Centre for Biomedical Ethics and Law, University of Leuven, Belgium*

Background: Residential psychiatric patients with severe persistent mental illness (SPMI) are often confronted with unbearable existential suffering. Qualitative research among patients suffering SPMI describes that they experience an existential loneliness due to difficulties in the development of human relationships. Being confronted with hopeless existential suffering of patients with a long-term need of psychiatric care invokes ethical questions about the content and the meaning of the therapy and care provided to these patients.

There is an emergent debate about the possible role of palliative care in dealing with hopeless existential suffering in mental healthcare. Patients with SPMI involving hopeless existential suffering raise the need for high-quality support and guidance within the framework of palliative care. The content meaning of palliative care in the context of mental healthcare has not yet been sufficiently explored. Apart from conceptual uncertainties, there also have been only very few attempts at empirical investigation.

Aim: This research aims at describing the characteristics of the care process for hopeless existential suffering of patients with SPMI, specifically from the psychiatric nurse's perspective.

Design: By means of a qualitative study design, we interviewed 15 psychiatric nurses in Flanders (Belgium) to describe how psychiatric nurses in Flanders (Belgium) deal with these patients. Data collection and analysis were inspired by the Grounded Theory approach.

Findings: In view of the empirical data the nursing support for the hopeless existential suffering of patients in need of long-term care can be described in terms of process-related development. In this process of care, four general phases are distinguished: meeting the patient, acknowledging the patient as an individual, building a personal caring relationship, and a concluding phase. The personal caring relationship between nurse and patient is the main element in this procedure. This relationship doesn't

just appear out of nowhere: it takes effort, from the moment of the first acquaintance on. During the first meeting whether there is a potential connection can be established. If nurse and patient 'have a connection', the patient can be acknowledged both as an individual and a sufferer. These are the foundations upon which the caring relationship is built. However, the above-mentioned general phases in the process of care shouldn't necessarily be viewed as successive stages: they are simply four pillars upon which the process of caring as described by the interviewees can be developed.

Inevitably, the caring relationship is framed in a specific context. This context can be either stimulating or restrictive to the relationship. Contextual factors as mentioned in these interviews can be categorized into three levels: the institutional level, the team level, and factors pertaining to the individual caring relationship itself.

Conclusion: Interpersonal relationships are identified as the core of the care practices for patients with SPMI which are confronted with existential suffering. Our findings describe a concretization of a relation based type of care or person centered care which can be considered as an essential element of palliative care.

### **Leadership in healthcare: Reflections from a care ethical perspective**

*Joke Lemiengre (1)(2), Linus Vanlaere (2)(3), Leentje De Wachter (1)(2), Liselotte Van Ooteghem (4)*

*(1) University College Leuven-Limburg, Belgium*

*(2) sTimul Care-Ethics Lab, Lubbeek, Belgium*

*(3) RHIZO, Kortrijk, Belgium*

*(4) GVO Woonzorggroep, Kortrijk, Belgium*

Background: Healthcare institutions face the clash between the dominance of a management approach mainly focused on advancing the efficiency and effectiveness of the care on the one hand, and the need to create a caring culture focused on the needs of care receivers on the other hand.

The complexity of the context in which leaders and managers in healthcare institutions operate requires an ethical reflection on how they can take on leadership in the daily practical organization of care.

International research on the issue of ethical leadership is mainly performed by social scientists with a focus on the ethical conduct and behavior of leaders. The focus of this project was to promote a deeper reflection on what leadership of staff members, team leaders, and managers of healthcare organizations from care ethical perspective means and encompasses in concrete daily practices.

Methods: By means of an action research, a conceptual scheme about the meaning of leadership from care ethical perspective was stepwisely developed. Firstly, readings and reflective discussions within the research team resulted in a draft version of a conceptual scheme that encompassed some characteristics of leadership from care ethical perspective. The conceptual scheme framed descriptions of concepts such as 'context', 'vulnerability', 'relationships', and 'power' in relation to leadership. Tronto's care ethics process (caring about, caring for, care giving, and care receiving) inspired both the content and approach of the development of an introduction training program in ethical leadership. As learning method, a learning community approach was chosen. Secondly, two

learning community groups were set-up, one group with leaders working in a nursing home setting, the other one with leaders responsible within a home care organization. The aim of the learning communities was to inspire the participants in their personal growth as a leader. During the meetings of the learning communities, participants learned through practical exercises and reflective discussions about the meaning of leadership from care ethical perspective. Finally, based on the insights of personal interviews and a focus group with the participants, the conceptual scheme with the description of the characteristics of leadership from care ethical perspective was attuned, and an evaluation of used methods to stimulate the learning processes was made.

Findings: Leadership of care ethical perspective deals with questions like “What is the line between ‘moralizing’ and ‘empowering care providers?’”; “How much patience do we have to support the individual learning processes of care providers within an organizational context of instrumental pressure?”; “How to deal with ‘mistakes’ and ‘failure’ in the care for care receivers who are dependent?”; “How to deal with the issue of power in leader– employee relationships”, ...?

The learning community approach is evaluated as a promising learning method for leaders in health care to reflect upon their ethical role. ‘Grass can’t grow by pulling’ seems to be an important adagio of care ethical leadership. However, the question how powerful this kind of leadership may be within the context of current health care organizations remains.

### **Ethical issues in mental health nursing in Brazil**

*Fernanda Cristina Lemos Mendes (1), Ronildo Alves dos Santos (1)*

*(1) University of São Paulo at Ribeirão Preto College of Nursing, Brazil*

Ethical issues arise naturally from the nursing practice, especially those related to psychiatric nursing. In Brazil, the offering of health care to patients in psychic suffering is still extensively discussed. Nurses have sought new ways to care for mental health patients, trying to focus primarily on out-of-hospital services, displaying an attitude of dignity and consideration, respecting each patient’s individuality and their own roles in their treatment as well as encouraging patient self-care and their social reintegration. On the one hand the “Psychiatric Reform”, which still being developed in Brazil, discusses new ways to offer health care to psychiatric patients and on the other hand the ethical issues related to the nursing practice are still seen from a deontological perspective and one of just following orders.

The objective of our research is to analyze and discuss with nursing professionals who work in mental health care the ethical issues that arise from their professional practice, based in the “Virtue Ethics” perspective which was devised by *Pellegrino* and *Thomasma*, who have focused mainly on the proposition of considering the point of “How I should be” instead of “How I should act”. From our point of view the “Virtue Ethics” perspective is essential to change the way Brazilian nurses comprehend Ethics in their professional environment.

**Effects of aging and their coping mechanisms among senior citizens in San Pablo City, Laguna: Basis for geriatric wellness program**

***Marc Lester Quintana (1)***

*(1) Laguna University, San Pablo City, Philippines*

No one can stem the tide of youth, for old age catches up with everyone. It is a global phenomena and one that needs to be addressed. The world has become more and more dynamic as the milieu changes. It is sad to note that the old are becoming less and less a priority. They slowly become pushed to the edge; from neglect to total abandonment. Hence this is not only a private concern but also a public. Their role in modern society is usually misconstrued as one that is detached and unrelated to the modern world. This critical lack of understanding and appreciation for them provides a denial point of our own humanity and mortality (McNichol, 2007).

Aging is a process that starts from the beginning of life. It is only in later life that changes due to aging become more apparent. These changes are manifested in the skin texture, flexibility of joints, eyesight, etc. Aging does not happen at the same rate for all individuals. Some older persons enjoy a more active life than others due to better physical fitness, a sharper and more alert mind, lack of visual or hearing impairment, and good body condition. Hence, this study was conducted to determine the effects of aging to the physical, psychological, social and spiritual conditions of senior citizens and their coping mechanisms.

The researcher used the descriptive-correlational design. The researcher conducted structured interviews to 175 senior citizens purposively chosen. Frequency and percentage distribution, weighted mean, pearson coefficient correlation and chi-square were used to treat the data.

Majority of the senior citizens were 73 years old, female, widow/widower, Roman Catholic, and enjoying pension from their retirement. The respondents experience spiritual aspects of aging, physical aspects of aging to a very much extent and psychological and social aspects of aging to a much extent. The senior citizens utilized to a much extent coping mechanisms in terms of their psychological and social aspects and to a moderate extent utilized coping mechanisms in terms of their physical aspect and spiritual aspect.

The physical, psychological, social and spiritual aspects of aging showed significant relationship with the different coping mechanisms. All of the demographic profile variables except for religion showed significant relationship with the coping mechanism of respondents. The coping mechanism employed by majority of the senior citizens are categorized as adaptive and palliative.

A geriatric wellness program was developed to help the aging population cope with the changes in life and maintain good health throughout.

## **Living and dying with Morbus Parkinson: Ethical challenges**

*Katharina Lex (1), Janine Rabe (1)(2), Jürgen Osterbrink (1), Stefan Lorenzl (1)(3)(4)*

*(1) Paracelsus Medical University Salzburg, Austria*

*(2) Kardinal Schwarzenberg'sches Hospital Schwarzach, Austria*

*(3) Hospital Agatharied, Germany*

*(4) University clinic Munich, Interdisciplinary Center for Palliative Medicine, Germany*

Background: Having been diagnosed with Morbus Parkinson, the life expectancy is 15 years on average. In the course of the illness symptoms worsen, which means extra suffering and severe obstacles for patients and their families. From international studies it is well known, that especially these patients and their families have tremendous palliative care demands which are seldom covered by local medical and/or care-provision-structures. There are no scientific studies available on how people suffering from an advanced phase of Morbus Parkinson (Hoehn & Yahr stage 3 or higher) are living in nursing homes (or private homes) in the city of Salzburg or the Salzburgian country side (Land Salzburg). Which care demands these patients and their caring relatives have and how they are dealing with the medical aspects of their illness are the research aims of our study.

Methods: The authors aim to include up to 50 "units of care": severely ill parkinsonian patients and their caring family members. The interprofessional research team (nursing sciences and medicine) uses a mixed-Methods Approach: with quantitative, validated assessments instruments the researchers evaluate the correct illness stage and scores are being risen: the data from this part will be analyzed with SPSS. In a second part, semi-structured interviews with the patients themselves, family-members and nurses are being conducted.

To analyze these data MAXQDA will be used. A content analysis according to Mayring will be done with the qualitative data. A positive ethical clearance from the Salzburg ethical committee exists.

Expected results: Through established Networks, via intensive telephoning with different nursing home providers, the local university hospital and a patient self-help-group the research team was successful in recruiting several parkinsonian patients and their families for our study. 2/3 of the included nursing-home-patients do not suffer from Morbus Parkinson, although they were diagnosed with this life-terminating-neurodegenerative-illness several years ago and were (partly) treated with appropriate, classical dopaminergic medication.

Discussion: When the study is finished, it will be the first empirical data-base on Parkinson patients in an advanced illness phase in Salzburg and the Salzburg country. We fear that not only being a "real" parkinsonian patient living and dying in a nursing-home setting is ethically very challenging, as for example only few nursing-home patients in Austria are involved in advanced-care-planning conversations and end-of-life-decision-making –e.g. deciding if an artificial feeding tube would be welcomed when dysphagia worsens; but being wrongly diagnosed and treated for Morbus Parkinson might have an enormous impact on the patients daily living and also on nurses perspectives.

## **Ethics, euthanasia and mental suffering of psychiatric patients**

Axel Liégeois (1)

*(1) University of Leuven, Brothers of Charity, Ghent, Belgium*

The Belgian Act of May 28<sup>th</sup> 2002 states that euthanasia is not a criminal offence under certain conditions, also in the case of mental suffering of psychiatric patients in a non-terminal situation.

From an ethical point of view, we distinguish three fundamental values at stake in euthanasia: the inviolability of life, the autonomy of the patient, and the care relationship between the persons involved. Ethical problems arise when these values are in a tension or conflict. In a relational and personalist ethics, we do not understand these values as absolute, but as fundamental values that can be assessed. Likewise, we do not conceive of these values as individualistic, but as relational values, so to be achieved in relations between people.

We embody this fundamental ethical approach in a two-pathway care process. The inviolability of life leads to the life perspective pathway. The caregivers, including nurses, support the patient so that he or she may find a meaningful life perspective, as an alternative to euthanasia. Together they search for alternatives in psychiatric recovery and rehabilitation, in palliative care and in existential and spiritual care. The patient's autonomy, on the other hand, leads to the euthanasia request pathway. The caregivers take the request for euthanasia seriously, clarify the underlying motives and check whether the request meets the legal conditions. The caregivers may assume the combination of the two pathways, or they can fully focus on the life perspective pathway while they appeal to a Leif-Physician, specialized in the pathway of the euthanasia request.

Based on the linking value of the care relationship, we make the connection between the two pathways by means of specific care requirements. These requirements are consistent with the legal conditions. Since the law is conceived primarily for euthanasia in a terminal situation of particularly somatic suffering, we endeavour to specify and concretize the legal conditions for the specific situation of euthanasia in case of mental suffering in a non-terminal situation. These care requirements are related to both pathways and enhance the dialogue between the parties involved. The first three care requirements are fundamental: (1) the request is 'voluntary' and 'well-considered', (2) the patient is in a 'medically futile situation of persistent and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder' and (3) there is 'no reasonable alternative' to the patient's situation (Euthanasia Act, 2002, art. 3, par. 1-2). The following care requirements are procedural: (1) conferring with the patient, (2) consulting of two physicians, (3) conferring with the interdisciplinary team, and (4) conferring with family and relatives. The ethical guideline we developed consists of a precise explanation of all these care requirements in the specific situation of psychiatric patients with mental suffering in a non-terminal situation. Moreover, when euthanasia is performed in a residential care facility, the advice of an ethics committee should be sought and every effort must be made to avoid a traumatizing effect of euthanasia to other patients.

## **A theoretical framework of patient autonomy in a highly technological care context**

*Catharina Lindberg (1), Cecilia Fagerström (2), Ania Willman (3)*

*(1) Blekinge Institute of Technology, Sweden*

*(2) Blekinge Research Council, Sweden*

*(3) Malmö University, Sweden*

Background: The concept of autonomy has recently gained increased importance in western health care due to its use to describe a patient's right and potential to make decisions about their own life situation. Patients in highly technological care environments are usually dependent on both formal/informal caregivers and technology, highlighting their vulnerability and challenging their autonomy. To understand the prerequisites for patients to experience autonomy and to support them, there is a need to enhance knowledge and understanding of the concept of patient autonomy in a highly technological care context. The development of concepts and theories in a practice discipline such as nursing, helps to improve both nursing care and nursing education [1]. Theoretical development is important when clarifying a discipline [2], hence, a theoretical framework could be of use to nurses in highly technological care environments to support and defend the patient's autonomy.

Materials and methods: When synthesizing research findings the work should be seen as interpretative and not aggregative in nature [3]. This study was an amalgamation of the results from three previous studies, carried out by members of the same research group, focusing on the phenomenon of patient autonomy from a patient perspective within a caring context. Three basic approaches of theory development: derivation, synthesis and analysis [4] provided an operational structure that also permitted the researchers to move back and forth between these approaches during their work in developing a theoretical framework.

Results: The preliminary results from the synthesis led to the understanding that patient autonomy in highly technological care environments is: To be in control though trust, co-determination, and transition in everyday life. The theoretical framework contains several components creating the prerequisites for patient autonomy. The preliminary results also put forward strategies that patients use to remain or obtain patient autonomy in highly technological care environments, i.e. the strategy of control, of trust, of partnership and of transition.

Conclusions: This study suggests an extended knowledge base founded on theoretical reasoning about patient autonomy, providing an understanding of the strategies used by patients to achieve autonomy in the role of patient. When possessing knowledge about the patient perspective of autonomy, the nurse/carer can avoid adopting a paternalistic or maternalistic approach. Instead, the patient can be considered to be a partner in care, allowing care to be provided that supports him/her in remaining/becoming an autonomous person in the role of patient.

### References

1. Sarvimäki A. Science and Tradition in the Nursing Discipline. *Scand J Caring Sci.* 1994; 8:137-142.
2. Pörn I. Enhet och mångfald i vetenskaperna [Unity and multiplicity in sciences]. *Finska Vetenskaps-Societeten (Febr.)*. 1985; 25-30.
3. Jensen L A & Allen M N. Meta-Synthesis of Qualitative Findings. *Qual Health Res* 1996; 6: 553-560.
4. Walker L O & Avant K C. *Strategies for theory construction in nursing*. 5th edition. Upper Saddle River, NJ: Pearsons Education Inc; 2011.

**When moral responsibility meets reality: Caring about the arising ethical dilemmas in diabetes care**

*Pei-Yi Liu (1), Helen Kohlen (1)*

*(1) Faculty of Nursing, Theological-Philosophical University of Vallendar, Germany*

This paper is based on a qualitative research project (dissertation) which investigates into the care logics in diabetes care practice with a focus on nursing and care ethics.

Care is fraught with ethical quandary. Caring for patients with chronic disease, care activities are expected flexibly regulated for each single circumstance. Ambivalences and tensions can be identified while care is taking place in the hierarchical and commercial practice. This paper describes three ethical dilemmas in the context of German diabetes care practice.

Accentuating autonomy with its emphasis on the patients' rights in decision-making, care is frequently performed in a passive way and may sometimes impede patients' safety. The first identified ethical dilemma 'autonomy in vulnerable bodies' reveals the ambivalence whilst healthcare workers see themselves limited by the business of serving their 'customers', but feeling obliged by their care ethos to offer therapeutic care to 'patients'; The second ethical dilemma arises when 'responsibility without authority' takes place. Healthcare workers' moral competence is strongly restricted by their legal rights. Noteworthy, physicians' authority influence patient-nurse-relationships subtly but powerfully even physicians are absent themselves from care activities. Distrusting relationships towards physicians, nurses and patients may be accordingly generated; To abide by the institutional standardization with economic expenditure in daily practice an ethically incongruent care may be delivered. The third identified ethical dilemma 'professionalism towards care boundaries' presents that healthcare workers feel pressure in assuming moral responsibility while care is offered inconsistent with professional identification.

By addressing care circumstances wherein ethical dilemmas emerge, the findings of the study stimulate a discussion about tinkering bodies rather than taming disease. Sharing responsibility instead of building blame may create a nourished care environment for reflecting ethical dilemmas.

**Understanding the meaning of body in the context of people with progressive cancer: A semantic concept analysis**

*Vibeke Bruun Lorentsen (1), Dagfinn Nåden (1), Berit Sæteren (1)*

*(1) Oslo and Akershus University College of Applied Sciences, Norway*

Patients with progressive cancer experience that the body changes as a result of disease and/or treatment. The bodily changes caused by cancer and treatment include emaciation, scars, hair loss, fatigue, ulcers, loss of limb(s), but also invisible changes in bowel, urinary and sexual function. Research studies have examined which symptoms that frequently occur in patients in palliative phase, and how patients experience living with advanced stage cancer. However, few studies have delved deeper into how people with progressive cancer experience living in a changed body.



Merleau-Ponty describes the body as the center of human experience. The body represents the patient's access to the world and to other people. The body is something we have and something we are. Any perception of the world involves perception of the own body. Merleau-Ponty seeks to describe the deepness and inner reality of the human being with his philosophy of the flesh. Flesh is both the individual's body and an element of being. It is the place where mind, body and world cross.

The aim of this study was to explore and understand the meaning and content of the concepts flesh and fleshly semantically according to the analysis strategy of Koort, and how this knowledge can enrich the understanding and meaning of body (flesh and fleshly) in the context of people living with progressive cancer. The interpretation of results shows that the body is the physical, vulnerable body that can feel shame and disgrace. At the same time the body has strength and dignity. The perishable body reminds people of time as perishable, but time has also a timeless dimension where people can experience renewal and alleviation.

Insight in metaphorical and literal meaning dimensions of flesh and fleshly might contribute to knowledge of the body in a wider and deeper sense, and hence how the body might be a provider of dignity. This knowledge might be essential for nurses in meeting patients with severe cancer disease.

### **Care and technologies: Delegation, discretion and virtualization**

Alain Loute (1)

(1) *Faculté de Médecine et de Maïeutique, Catholic University of Lille, France*

The objective of this paper is to understand how theories of care can be mobilized in the field of e-health and telemedicine, a peculiar and recent field situated at the crossroads of digital interactions of care, management of digitalized medical data, prostheses and/or digital implants that could repair bodies or increase body's capacities. The theories of care (a.o. Tronto, Gilligan) have renewed the vision of care and health, particularly in the manners in which care is provided. The fact that caring for the vulnerable (esp. children, the disabled, the elderly, the demented) is most often devolved to women, black people, migrants, e.g. people at the intersection of gender, class and race domination, interrogates such the value of care as the classical ethical values, traditionally erected as universal.

Besides, care activities are entrusted mostly to women, care activities also tend to be entrusted and delegated to the technology. Numerous research and innovations in e-health are emerging, thanks to political and economic strategies of promotion and funding<sup>1</sup>. They appear to be able to enhance or to second the traditional care actors, ranging from medical or paramedical actors. Another common point between care activities and digital device of care is its discretion, considered as a virtue. This dual characteristic of the delegation and the discretion of the care concerns both the care produced by technological artefacts and the care provided by the traditional providers of care. This comparison of technologies and care providers has various effects that need to be addressed.

On the one hand, it questions the very status of technologies and care practitioners. Are technologies available to supplement caregivers? Or are technologies real actors, possessing of course characteristics of care but obeying nevertheless to instrumental rationality? On the other hand, it raises new questions about the significance of the delegation of the care in the field of ethics of care. If one thinks that one goes from a delegation of the care to the dominated to a delegation to the

machines, how to understand this choice? Is it a choice that denies the recognition of the dominated, in favor of machines? Or on the contrary, a choice which, thanks to the machines, makes it possible to free oneself from domesticity? Do the technologies favor "attention" to others or are they more precisely a form of capture and disciplinization of attention<sup>2</sup>? Do the delegation of care to technologies mean that the care could be "robotized"? Finally, we must also question the meaning given to *discrete* and efficient machines. The discretion of care can be reflected, in technological terms, in the *virtualization* of artifacts. Virtualization of digital technologies is neither neutral nor harmless; Its effects are reflected in terms of the extension and intensification of the purposes of technology: temporal and spatial extension of the supervisory power and intensification of the normalizing effects of technology<sup>3</sup>.

<sup>1</sup>Cf. Jean-Philippe Cobbaut and Alain Loute, "What ethics for telemedicine?", in L. Menvielle and A.-F. Andrain-Pontevia (eds.), *The Digitalization of Healthcare: new challenges and opportunities*, Palgrave MacMillan, to be published.

<sup>2</sup>Cf. Bernard Stiegler, *Taking Care of Youth and the Generations*, Stanford, Stanford University Press, 2010; Crary, Jonathan. *24/7: Late Capitalism and the Ends of Sleep*, London and New York: Verso, 2013.

<sup>3</sup>Cf. Grandjean & Loute, "The Materiality of Virtuality: Towards an Intensification of Invisibilities", In *Critical Studies on Security*, submitted 2<sup>nd</sup> of December, 2016.

### **Caring for a mother with dementia: Two accounts on experiencing vulnerability**

*Ina Luichies (1), Esther Hanse (1), Anne Goossensen (1)*

*(1) University of Humanistic Studies, Utrecht, The Netherlands*

The ageing population is growing rapidly and the government faces increasing pressure to provide the elderly with adequate care, however expenses are cut down. Thus, a growing number of children have become carers for their ageing parents. These children are confronted with the increasing vulnerability of their ageing parents and experience considerable difficulties. They are entering unknown terrain, where they have to come to terms with the dependency of the persons they used to be dependent on. For many children this is a major challenge. So far research exploring this area has focused on concepts such as burden, wellbeing and duty. There are few qualitative studies related to the experience of the encounter with a vulnerable parent. Therefore the central question this study addresses is: what themes can be distinguished across children's experiences of taking responsibility for their ageing parent?

Our study takes inspiration from the expressive-collaborative view of Walker (2007). According to Walker the vulnerability of the other makes people responsible, and people come to understand themselves through the way they handle and express their responsibility in daily practice. Accounts of understanding are socially (collaborative) constructed. In this qualitative study, we analysed two Dutch autobiographical books by two adult siblings, a brother and a sister, both caring for their ageing mother affected by dementia. The books were analysed in three steps. At first we derived a naïve understanding which resulted in the portrayal of the mother, son and daughter. In the second step we performed a thematic structural analysis and we identified different meaning units for the son and the daughter each. In the last we compared their experiences and reactions, and reflected on the themes in relation to the research question.

Tensions emerge as an integral theme of the caregiving experience. Several dimensions appeared which clarify the tensions expressed. We found six complementary sets: holding on to autonomy or accepting dependency; searching for truth or compromising with non-truth; focussing on the parent's emotions or own emotions; grieving for the loss of the previous parent or relating to the present parent; fighting or accepting the suffering; holding on to family responsibility or relinquish responsibility to professionals. The understanding of these themes, augmented and improved through a discussion from a care ethical perspective, drawing upon theoretical and philosophical viewpoints of Ricoeur and Walker.

We argue that understanding tensions as an unavoidable and complementary phenomenon, can help professionals support caregiving children, and the children themselves to sustain the caregiving role and to improve the quality of care.

### **What do we know about ethical aspects of spirituality in care?**

Olivia Lujnenburg (1)

(1) *International Care Ethics Observatory, University of Surrey, UK*

Increasingly, spirituality is a phenomenon of debate in general and, most particularly, in care settings. It is a topic that brings up ethical questions regarding needs and interests of care-givers, care-recipients and family members. This presentation summarises the body of literature regarding the ethical implications of spirituality in residential care for older people. It examines the following questions: What does the literature so far reveal regarding ethics and spirituality in residential care for older people? What are the different philosophical and theological definitions underpinning spirituality and spiritual needs in the care for older people? And to what extent have spiritual needs been explored in previous and current residential care for older people? The literature review will also refer to ethical dilemmas that arise for care organisations regarding the expression of spirituality in care. By way of conclusion, there will be a discussion of the future research agenda relating to ethics, spirituality and care.

### **Educating to “Hope-inspiring competence” in nursing: Clinical and ethical aspects**

Melissa Maioni (1), *Maria Teresa Russo* (2)

(1) *Institute of Philosophy of Scientific and Technological Practice – Campus Bio-Medico University, Rome, Italy*

(2) *Roma Tre University, Rome, Italy*

The role of nurses in personalized support and in the care of patients is of paramount importance, in particular of those whose life is coming to the end, not only in professional terms, but also from a human point of view.

Sometimes, in fact, the patients can ask nurses questions about the meaning of life, to which is difficult to answer. In some cases the illness can lead patients to desire death or to voluntarily put an end to their existence, because of the despair they feel about the recognition of the limited and fragile human condition, and the loneliness due to the disorienting pain e suffering.

We want to investigate to which nursing competence learned during the academic career, this ability which is required by clinical practice could correspond to.

A hypothesis has been identified in the “Hope-inspiring competence”, previously introduced in literature in the psychiatric rehabilitation’s field by Russinova<sup>1</sup>, which echoes in the nursing field to the concept of “restoration of being”, explained twenty years before by Vaillot<sup>2</sup>, whereby the “hope-inspiring competence” must be a specific and essential ability of “being” a nurse. They will be able to transmit hope significantly better depending on who they are, than what they do.

The professional knowledge, specific techniques and other competences are necessary, but there are some skills that a professional has and must have to be a nurse, and hope is one of them.

It is essential that we discuss what are the suitable training tools to educate future nurses to hope so that they could develop a more refined moral sensitivity and an appropriate nurses’ ethical competence.

#### References

1. Russinova Zlatka, “Providers Hope-Inspiring Competence as a Factor Optimizing Psychiatric Rehabilitation Outcomes”, *Journal of Rehabilitation*, 1999, 16(4), pp. 50-57.
2. Vaillot, M., “Living and dying: Hope: The restoration of being”, *American Journal of Nursing* 1974, 70 (2), pp. 268-273.

#### **Privacy or information during bedside briefing: Who decides what matters at the point of care?**

*Simon Malfait (1)(2), Van Hecke A (1)(2), Van Biesen W (1)(2), Eeckloo K (1)(2)*

*(1) Ghent University Hospital, Belgium*

*(2) Ghent University, Belgium*

Background: Discussing the patient’s situation at the bedside, e.g. bedside briefings, is an increasingly common practice in healthcare services. It enhances patient safety, involvement, and bilateral awareness of the current situation. Several studies have identified potentially relevant nurse-reported barriers during bedside briefings, with many similarities between countries. While most of these barriers are of a more practical nature (e.g. time-consumption), one barrier relates to the ethical dilemma of breaching patient privacy. Nurses report feeling awkward about infringing the patient’s privacy in semi-private rooms, and use this argument to support their reluctance towards bedside briefings. Remarkably, there is almost no research on patient opinions on this relevant issue.

Materials and methods: An ongoing multicenter, longitudinal study on feasibility, appropriateness, meaningfulness and effectiveness of bedside briefing allowed capturing additional information on privacy issues. Interviews with nurses (n=100) and patients (n=40), and observations of bedside briefings (n=400) were conducted on a variety of nursing wards. Content analysis was used to analyze the interviews and identify the patients’ and nurses’ opinions. Quantitative methods were used to analyze the observations.

Results: About 60% of the nurses report the infringement of privacy as an important barrier for not using bedside briefing. A significant number of patients express a diverse need for more information, although their attitude towards bedside briefing differs. Patients in private rooms are more concerned

with their privacy, consider bedside briefing as a possible privacy-infringing method, and indicate that, amongst other reasons, such infringements are one of the reasons why they insist on having a private room and are willing to pay extra for it.

Patients in semi-private rooms report that they have lesser expectations towards privacy and that their privacy is often already substantially infringed. They indicate that information is, mostly unaware, often shared in semi-private rooms. Additionally, patients indicate that they are convinced that nurses are professional enough to be cautious with sensitive information. Moreover, patients indicate that they often tell disease-related information to their neighbors, if these are non-familiar persons. During the observation, no patients refused a bedside briefing. The results indicate that patients in semi-private rooms are less concerned about a possible privacy breach during bedside briefings if it provides them with more information. Patients sensitive for breaches of privacy often opt for a private room.

Discussion and conclusion: The implementation of bedside briefing is often blocked by the argument that it will infringe patient privacy. Our findings indicate that patients are less reticent towards receiving information at the bedside, even if this possibly infringes their privacy. The findings that the patient's perspective in this issue is understudied, that the nurses' perspective is apparently decisive on this matter, and the determined behavior of nurses to protect the patient's privacy could indicate that the ethical standards, legislation, and professional codes of nursing practice are not yet adjusted to the call for more citizen participation. This evokes the question whether society should prioritize the ethical principle of information or of privacy, especially taking into account the financial burden of semi-private rooms.

### **Lived experiences of Iranian patients regarding dignity maintenance**

*Arpi Manookian (1), Mohammad Ali Cheraghi (2), Alireza Nikbakht Nasrabadi (3), Mahboobe Shali (1)*

*(1) Nursing and Midwifery School, Tehran University of Medical Sciences, Tehran, Iran*

Dignity maintenance and promotion frequently emphasized as a basic patient's right in national and international nursing code of ethics and considered as an ethical responsibility of a professional nurse. Therefore it is essential to elicit patients' lived experiences in order to explore the authentic meaning of the patients' dignity maintenance and provide a dignifying care for them. The present study aimed to discover the lived experiences of Iranian patients regarding their dignity maintenance at the bedside. This qualitative study was conducted using an interpretive phenomenological approach. A total of 14 participants (9 women and 5 men) were purposefully selected, and data were collected using individual in-depth semi-structured interviews. The recorded interviews were transcribed and analyzed by the Diekelman, Allen and Tanner approach. The findings of this study revealed three main themes and related subthemes regarding the meaning of preserving patients' dignity. The first main theme was "exigency of preserving the innate human dignity" with its subthemes as: "respect for the intrinsic equality of all humans" and "treating the patient as a valued person, not an object". The second theme was "service based on love and kindness" with its two subthemes as: "being with the patient" and "inspiring the sense of being accepted and loved". The third main theme emerged as "dignifying and transcendental professional service" with its subthemes as: "professional commitment to uphold patients' rights" and "enlightened practice". This study revealed that the patient's dignity maintenance depends on nurse's moral obligation to manifest the human love that is in their own as

well as their patients' nature. In conclusion, if the nurses reflect on the transcendental nature of their profession, they will value and prize their everyday nursing practice and will benefit from caring capacity for their own self –actualization and enlighten.

**Religion, worldviews and pediatric palliative care decisions among undergraduate students at two Croatian universities: A questionnaire study**

*Renata **Mardetko** (1), Darko Hren (2), Anto Čartolovni (1), Dalibor Čavić (1), Damir Miloš (1), Marta Čivljak (1), Dario Sambunjak (1)*

*(1) Catholic University of Croatia, Zagreb, Croatia*

*(2) University of Split, Croatia*

Background: Previous research has identified various influences of religion and worldviews on attitudes and decision making in relation to beginning and end of life. Death and dying in childhood is a traumatic experience which requires not only the palliative care for child, but also support for their family members and carers, who may find solace in their religious practices or worldviews. This topic has not been much explored, although it has a significant importance for better understanding and improvement of paediatric palliative care and support as well as understanding of the ethical aspects of palliative care.

Aim: Explore the relationship between religion and worldviews and decision making about the end of life and paediatric palliative care among undergraduate students at two Croatian universities (Croatian Catholic University in Zagreb and Faculty of Humanities and Social Sciences, University of Split. Furthermore, we will compare attitudes of nursing students and other students and look into connection between demographics and religion and worldviews and opinions about life and death.

Methods: A questionnaire study will be conducted among the first year undergraduate students (Nursing, History, Sociology, Communication Sciences, Psychology) at the Croatian Catholic University in Zagreb and at the University of Split Faculty of Philosophy (Pedagogy, Teacher Education, Early and Pre-School Education). An anonymous questionnaire will consist of three groups of questions: general and demographic, religion and worldview (based on Gielen at al. 2011) and questions about death and dying in childhood (incl. abortion, euthanasia, withholding of special procedures in paediatric palliative care, decision making at the end of life and presence of siblings in the last days of patient's life).

Results/conclusion: The survey was conducted in late February and early March 2017. This will be followed by the data analysis and presentation of results. The study will contribute to better understanding of factors related to end of life decisions and paediatric palliative care among younger population. It will also provide the comparison between the nursing students and students of other professions, which is important as the decisions about death and dying, with all their ethical aspects, involve not only health professionals but also population in general. The insights into nurses' views about paediatric palliative care and sensitive end of life issues will inform further development of clinical practice and nursing education.

This study is funded by the Catholic University of Croatia (project HKS-2017-4 titled 'Religiosity, worldview and attitudes towards sensitive palliative care issues among undergraduate students at two Croatian universities').

## References

Gielen J, Van den Branden S, Van Iersel T, Broeckaert B. The diverse influence of religion and world view on palliative-care nurses' attitudes towards euthanasia. *Journal of Empirical Theology*. 2011;24:36-56.

## **Surrogate decision making and the taboo around long term tube feeding (PEG) at advanced dementia in residential facilities: A qualitative study**

***Rosa Mazzola*** (1)(2)

(1) *University of Bremen, Institute for Public Health and Nursing Research, Germany*

(2) *Ostfalia University of Applied Sciences, Faculty of Health Sciences, Wolfsburg, Germany*

Introduction: Surrogate decision making regarding health care treatment for family members often come along with uncertain and important distress, especially considering the long term tube feeding treatment in advanced dementia. In Germany and other European countries it is estimated that 5 to 9 percent of nursing home residents get food not only by mouth, but also via tube feeding. The special challenges when making surrogate decision on tube feeding at advanced dementia in residential facilities are:

- Evidence is low to determine the effects on survival, nutrition and aspiration
- Unknown residents' values or preferences regarding enteral nutrition
- Decision making by family members.

Objective: To explore a better understanding of what is going on when making surrogate decisions on tube feeding at advanced dementia in residential facilities.

Methods: From 2010 to 2012 qualitative research on the basis of the Grounded Theory approach, with retrospective design was carried out in Bremen, Germany. Sixteen residential facilities delivered data of residents who underwent PEG-event. In addition, case-related, semi-structured interviews with surrogates, nursing home physicians, nursing staff and other persons involved, were performed. Consequently a single-case and a cross-case analysis were conducted. Expert-interviews were carried out to get more context information about decision making at hospital.

Results: Overall 31 interviews were conducted with authorised family members for residents with dementia and tube-feeding decision making, physicians and nursing staff. Mostly, family members who functioned as patient's authorized surrogates expressed the tube feeding event as "life-or death decision" for their loved one. They feel, that there is no other option. Surrogates concluded that deciding against tube feeding is like dying of starvation. The criteria "Severity dementia" and also patients' values have obviously only a marginal influence on PEG decision-making.

What are crucial criteria in making surrogate decision on tube feeding for patient without decision-making capacity near end of life?

Family members seem to be insufficiently empowered and overburdened in acting as surrogates. Surrogate decision making to others was reduced to "life-or death decision". The results suggest there is no informed consent, instead - there is a misinformation in surrogate decision making. A misconception exists concerning the consequences to forgo tube feeding. This false belief interacts with a misconception of starvation.

Conclusion: The responsible person require competences in decision-making, otherwise the misconception, individuals starve, strengthens the moral aspect in end-of-life conversation.

Facing a surrogate decision making to others - the responsible health care team – need

to use neutral language and patient-oriented information,

to provide evidence base health information,

to use decision aids systematically,

to avoid acting under time pressure.

Finally, nursing staff has to act self-determined in decision making near end of life.

### **Three decades of moral distress research: So what?**

*Joan McCarthy (1)*

*(1) University College Cork, Cork, Ireland*

In 1984, Andrew Jameton, delineated the term, moral distress, in order to capture what he saw as a fundamental feature of the professional role of nurses. Jameton's account of moral distress focussed on the way in which external constraints, such as institutional policies and practices, can prevent nurses from acting in accordance with their personal and professional ethical values and his definition has largely informed the qualitative, quantitative and argument-based research that has been undertaken on moral distress in the last three decades. This research has found that the experience of moral distress among health professionals contributes to staff demoralization, desensitization and burnout and, ultimately, to lower standards of patient care.

Despite the widespread deployment of Jameton's definition of moral distress in the empirical studies that have operationalized it, some authors have found fault with his delineation. The main objection to what I call the standard account of the term, moral distress, is that it does not pick out a discrete phenomenon or set of phenomena. Authors point to the absence of any agreement on the key features of the concept (e.g. it is too narrow or too broad) and, in turn, the difficulties that follow in devising tools to measure it adequately.

In this presentation, I re-examine the standard definition of moral distress. I suggest that the important question is not, what is moral distress? But rather, who is talking about and researching moral distress and why are they interested in moral distress at this time? Given the increasing pressure on nurses and other health professionals worldwide to meet efficiency, financial and corporate targets and the implications of these for standards of patient care, I will argue that moral distress is best viewed as a conceptual tool that brings the emotional landscape of the moral realm to the fore and draws attention to the socio-political and contextual features of moral agency.



### **Qualitative study on communication and awareness of diagnosis and prognosis with advanced stage cancer disease**

***Paola Melis*** (1)

(1) *University of Cagliari, Sardinia, Italy*

In the area of cancer care, the discussion on the communication of the diagnosis and prognosis to the patient has been studied since a long time ago. Most of the time the focus is on informations giving and comprehension of those informations and health professionals' competencies as well, but communication is really complex and comprehensive.

In this research patients, proxy-relative, doctors and nurses are considered as a "communicative nucleus": their perspectives about communication and awareness of diagnosis and prognosis in an advanced stage of the disease are simultaneously compared to understand how they are situated and what perception of each other they have.

Qualitative study. Another aim of this study is to understand what ethical principles, in respect to diagnosis' and prognosis' knowledge and communication, guide doctors', nurses', relatives' caring of patient with cancer in advanced stage

To analyse data it has been adapted the IPA methodology, as the aim is to develop an interpretative analysis of data, starting from the description of individual's experienced phenomena and going through an integrated analysis of the four perspective. This study recognize the relevance to the meanings that are created through interaction and, in this sense, wants to offer an insight of the activity of health professionals working as a unit.

Data have been collected through semi-structured, in-depth, one-on-one interviews to patients with cancer in advanced stage and a life expectancy of less than 1 year, the relative-caregiver, their referring physician, their referring nurse (46 interviews in total).

Several procedures have been followed to ensure the validity and rigour of this study: the Lincoln and Guba's four-criterion gold standard and Giorgi's suggestions as well.

Comparison of the four perspectives has provided an insight about the convergences and divergences about expectations and feelings and assumptions in the four perspectives on communication related to diagnosis and prognosis. It has also outlined the level of awareness of the integration of communication among health professionals.

### **Advance directives, dementia and end of life in nursing homes**

***Marion Droz Mendelzweig*** (1)

(1) *Research & Development Centre on Aging & Health, Institut et Haute Ecole de la Santé La Source, Lausanne, Switzerland*

Background: In 2013, Switzerland implemented a revised article in the law governing the protection of vulnerable adults. One direct implication this act has on nursing homes' working procedures is the enforcement of a formal healthcare plan for every resident entering the institution. Advance directives (AD) and informed decision about end-of-life care stand at the core of the concern. Focusing on residents deprived of their capacity to offer an opinion, our study investigated how nursing homes'

healthcare professionals scrupulously observe the residents' wills, while knowing that AD are not commonplace use among elders.

Methods: A questionnaire has been submitted to every professional in charge of palliative care in each of the Canton of Vaud's nursing homes (N=121, number of replies=69). The questions aimed to gather details on the most frequently mentioned intentions put forward by residents, and on the institutional measures taken by the staff during their end-of-life care. Qualitative interviews (N=10) completed the data on the institutions' specific guidelines for end-of-life care. They evolved around the principles governing these guidelines. Working procedures aiming to determine a decision making process was a central aspect taken into consideration in the study.

Results: Replies show that procedures for end-of-life care do exist and are implemented in nursing homes. Appointment of a staff member specifically in charge of palliative care on one hand, and elaboration of "homemade" forms aimed to collect indications about the residents and their family wishes on the other, are the main steps taken by nursing homes following the rise in public concern for end-of-life conditions, in particular in situations of dementia. Healthcare professionals' capacity to adapt the end-of-life healthcare planning to each specific situation, through an ongoing dialogue with the residents and their relatives, is the major characteristic of nursing home settings.

Conclusion: Healthcare professionals' feeling of confidence in the accordance of their interventions with the demented residents' wills is largely dominating their perceptions. The spirit of the law is being respected, although inherent contradictions stem from the intersection of the law with the ethic of end-of-life care in situations of dementia: encouragement to establish AD requires precise, formalized and written data, while nursing home professionals' experience in end-of-life care calls for keeping an open dialogue with the patient and with his relatives, till the very last moment of life. Facing this tension, two major types of nursing homes emerge: one encouraging a narrative approach in relation to the demented resident, building on a collaborative and rather informal involvement of all staff members in the collection of information worth considering for his care. Another approach follows the conviction that introducing systematic procedures will progressively improve the nursing home ability to behave in accordance with the legal requirements. Whatever is the dominant pattern of organisation, uncertainty stands as the core issue in end-of-life care in demented persons.

### **Bad news information: Nursing integrative literature review**

*Cassiana Mendes Bertoncetto Fontes (1), Maria Helena Borgato (1), Daniele Vieira de Menezes (2)*

*(1) Universidade Estadual Paulista "Júlio de Mesquita Filho", UNESP- Botucatu, SP-.Brazil*

*(2) Hospital de Câncer de Barretos, SP- Fundação Pio XII, Brazil*

Objectives: Describe how bad news information process is established and identify how nurses deal with bad news information.

Method: Integrative literature review including articles published in Portuguese and English language during the period between 1993 - 2014 in Bireme, PubMed, Scopus, Web of Science, Embase and CINAHL databases. Nine articles were elected by selector flowchart. It was filled an electronic file, a list to consolidated criteria for Reporting Qualitative Research and checked the level of scientific evidence for each article.

Results: 99 articles were identified and included nine articles through selector flowchart. Informing bad news is common in oncology and palliative care areas; the nurse autonomy is culturally hard influenced during the process.

Conclusion: The nurses' skills and the way they act during the process influence the reaction of the patients about the message. The subject is scarce in the literature and need to be explored.

### **The experience of the vulnerability of nurses concerning care process in the Pediatric Intensive Care Unit**

*Cassiana Mendes Bertoncetto Fontes (1), Maria Helena Borgato (1) Flávia Mendes de Sá (1)  
Lídia Nunes Vieira (1)*

*(1) Universidade Estadual Paulista "Júlio de Mesquita Filho", UNESP- Botucatu, SP-Brasil.*

Introduction: The process of care in the Pediatric Intensive Care Unit (PICU) involves the principles of autonomy and vulnerability, tenuously contextualized in the interpersonal relationships, on the attrition generated by professional stress, and the risk inherent to patient care. The principle of autonomy guides the relationship existing between health professionals and patients and contributes in a harmonious way concerning feeling, thinking and acting. This independence is characterized as the right to participate and consent to decisions.

The term vulnerability is polysemous and implies on a sense of disaster or danger, derived from the Latin verb *vulnerare*, which means "to cause injury or injury." It can also "designate people's susceptibility and damage to health." The most current concept of vulnerability corresponds to bringing abstract elements associated with, and associable to the processes of illness.

Vulnerability can be observed in health professionals, institutions, managers, internal health policy or the whole system. Thus, it is intended to understand the vulnerabilities of the process of taking care in the practice of the nurse of a PICU and this context can contribute to the foundation of ethical principles practice, of beneficence and non-maleficence.

Objective: To understand the vulnerabilities of the process of care in a PICU environment

Method: Qualitative study, realized in a PICU of a public teaching hospital, approved by Ethics Committee. All the nurses that worked in the unit and agreed to participate were included in the study. The interviews were, conducted by the researchers and did not affect the nurses' activities, with 20 minutes duration. The instrument of data collection was composed of identification and two guiding questions:

1- Explain your concept about vulnerability?

2- How do you experience vulnerability in the process of care for hospitalized patients at PICU? The Content Analysis was applied to identify meanings; the speech units were categorized, and the themes that evidenced the reality.

Results: 9 (100%) of the interviewees are female; they have specialization course; average time of graduation and assistance work of five and a half years; average working time in PICU of 2 ½ years. The categories coming from the analysis of the first question were: emotional, physical and social exposure of the nurses; fragility of the child; risk of event and being exposed to anything and to the environment; infection; biological accidents; adverse events; physical, biological and emotional risks.

The categories related to the second question were: two-way vulnerability; to feelings and emotions; palliative care; family; impotence; exposure to the environment; lack of material; accidents with sharp cutting material; lack of autonomy and care centered on medical treatment.

Conclusion: The subjects which identified comprehension about the concepts of vulnerability of nurses were: range of exposure, that is, a broad concept that involves emotional, relational, environmental and inherent risks of intensive practice; vulnerability of the nurse towards the fragility of the child, that is, the restricted concept of a single path; vulnerability of the nurses to decision making and the degree of autonomy.

### **Nursing ethics education: A critical examination**

Aimee Milliken (1), Pamela Grace (1)

(1) Boston College, Brighton, USA

The status and effectiveness of nursing ethics education has been a subject of debate in recent years in the United States (US) and internationally. While preparing nurses to recognize and address ethical issues in practice is recognized as an obligation of undergraduate curriculum and beyond, a consensus regarding the best mechanisms for accomplishing this remains elusive. Evidence suggests that questions remain about the adequacy of nursing ethics preparation, and that nurses in practice feel ill equipped to face the reality of today's healthcare environments. In this paper, we take a critical look at nursing ethics education. Using the US as an exemplar, we first review the state of nursing education in general, situated within the context of higher education, including an examination of the curricula "essentials" of Baccalaureate, Masters, and Doctoral programs. We then focus on the state of nursing ethics education with the goal of evaluating its nature, prevalence, and effectiveness. Finally, based on this review, and an argument for the critical importance of ethics education for good nursing practice, we suggest educational policy implications for nursing ethics at a curricular level.

### **Addressing vulnerability in the clinical setting**

Settimio Monteverde (1)

(1) University Hospital of Zurich, Institute of Biomedical Ethics and History of Medicine, University of Zurich, Switzerland

The idea that patients are vulnerable has first emerged in research ethics which the description of how researchers should address the different risks of research participants to suffer physical or psychological harm. From clinical trials to medical procedures, speaking about vulnerability means taking a closer look to the different sources of harm patients are exposed. Criticisms brought forward argue that the term is conceptually vague with two line of arguments: On one hand, too broad definitions "soak" the concept by covering virtually every recipient of care. On the other, too narrow definitions rely on substitute concepts that better explain what vulnerability effectively entails, like compromised decision-making capacity, unrealistic hope of a cure or excessive reliance on medical authority. Interestingly, these criticisms seem not to affect the talk about vulnerability in the clinical setting. In contrast to theoretical debates, healthcare professionals find it easier to identify vulnerable

patients than to offer a robust and exhaustive account about what vulnerability is. In the light of these findings, overcoming the gap between acknowledging vulnerability and not being to offer a solid account about the concept has become an ethical imperative.

Under the auspices of the Swiss Federal Office of Health, a nationwide platform of healthcare providers was created to gather institutions willing to foster equity in the provision of healthcare in increasingly diverse settings. The Clinical Ethics Unit of the University Hospital of Zurich was commissioned by the Executive Board to represent the hospital in the national platform and to investigate the phenomenon both from a conceptual and from a clinical point of view. The presentation will first offer a succinct description of the conceptual work which has been done. Findings of two consecutive surveys of ethics resource leaders from the clinical departments will be presented. They merge in a taxonomical model of vulnerability with four distinctive features: The first is that vulnerability is originated in the *diversity* of needs people have and these needs affect health outcomes. The second is that these needs are *sectorial*, i.e. rooted in the personal, socioeconomic, age, literacy or health sector. The third is that vulnerability is experienced as *structural*, i.e. enforced by the hospital setting itself in which the resources usually available to the person (e.g. neighborhood, spouses, children, interpreters, social workers, etc.) are not available now. The fourth is that the degree of vulnerability is *intersectional*, i.e. patients with vulnerabilities in different sectors show a *disproportionate* increase in vulnerability and risk for worse health outcomes (e.g. asylum seekers listed for liver transplant). The diversity of needs, their sectorial nature and the intersectional effect of multiple needs are presented as findings that justify the talk about vulnerability in the clinic. They can serve as starting points for assessing and addressing vulnerability in the clinic in the view of a fair and sustainable distribution of health-related outcomes.

### **Reasons for non-beneficial treatment at the end of life in a palliative care population with cancer: A systematic review**

*Marleen Moors* (1), *Quinten de Bakker* (1), *Anne Goossensen* (2), *Maryska Janssen-Heynen* (1)

(1) *VieCuri Medical Center, Maastricht University, The Netherlands*

(2) *University of Humanistic Studies, Utrecht, The Netherlands*

Clinical decision-making at the end of life has gained complexity in the last decades due to an increased amount of life-prolonging treatments and pain relief. Studies show that non-beneficial treatment at the end of life with chemotherapy and/or other opioids occurs frequently. This raises the question how far medical care should go in treating palliative patients in the last phase of life. We conducted a systematic review to gain insight in the reasons for non-beneficial treatment of cancer patients in a palliative phase of illness, the medical measures that took place most frequently and which processes, infrastructures, individuals and interpersonal dynamics led to an increased risk of non-beneficial treatment. We searched several databases (PUBMED, EMBASE, CINAHL, PsychINFO), hand-searched literature, Google scholar and Research Gate from 1945 to January 2016. This review suggests that the reasons for non-beneficial treatment at the end of life are multifarious and complex. Despite the lack of agreement among researchers about the definition of non-beneficial treatment in a palliative care population, findings suggest that pressure from family to continue treatment, a lack of dialogue about

end of life decisions prior to the terminal phase of illness, uncertainty about prognostic factors and ethnic and cultural differences are contributing factors.

### **The meaning of life and death in the oldest-old people: The Re-Aging Gerontology and Vertical Communication**

*Naoki Morishita (1), Masami Matsuda (3)*

*(1) Hamamatsu University School of Medicine, Japan*

*(2) Tokyo Kasei-Gakuin University, Japan*

In Japan, the number of centenarian has already surpassed 65,000 as of 2015. And 10% of the total population is over 80 years old. The direct factors of super-aging society are longevity, declining birthrate, depopulation in certain places, and so on. Under these conditions, the gap between the rich and the poor is increasing in all generations.

There are four approaches to deal with the challenge to this bipolarization. The first is reforming labor markets to recruit the old, women, robots, and foreigners. The second is remaking social security systems like the pension. The third is reconstructing access to mutual help, including volunteer activities. And the fourth is reconsidering our view of human beings, life, and death to enable us to adapt to a super-aging society.

The most important key to this challenge is the old generation who are connected to all the approaches. Indeed, the participation of the healthy old in various social fields should be encouraged more. However, only two modern types of old people have been described. One is “the passive type” who depend on family care. The other is “the active type” who are enjoying life, being independent and putting emphasis on pleasures. Therefore, a new comprehensive view of aging is needed.

We propose the concept of “re-aging gerontology” to establish this view. The word “re-aging” means that aging is not the state but process of our life, which is being continually reconsidered. Imaging a life span of 100 years, in which the old can be classified into four stages: pre-old (from 51 to 64), young-old (from 65 to 74), old-old (from 75 to 84), and oldest-old (over 85). “The passive type” may be suitable to the old-old, whereas “the active” may be more suitable to the pre-old. Re-aging gerontology re-classified the young-old as the agent to form communities, that is, “the community-forming type.”

Nevertheless, there is no clear answer to how the oldest-old behave, of whom belong over 5 million people in Japan. They often do not express any desire about their future and seem not to care about themselves. These may be called “the completely passive type” or “the self-neglect type.” We have to consider how to encourage them from the perspective of “re-aging gerontology,” not of Tornstam or of Ericsson. It is because those models and that of Zen Buddhism cannot be applied to an overwhelming majority of contemporary and future Japanese.

In this presentation, the focus is on the new model for the oldest-old from the perspective of “re-aging.” A clue can be found in so-called “consolation communication” between those who have passed away and the living, which is supposed to exist in human beings universally. This communication is included as part of “vertical communication” along the axis of irreversible time from birth to death. Vertical communication needs a “vertical community.” When the oldest-old can form their own

community, they can have their own meaning of life and hold the hope to be together with familiar others even after their death.

### **Fields of action to maintain autonomy and dignity in the care of older people with dementia**

*Nujic Majda (1), Zellner Manuela (1), Marie-Britz Sarmiento (1), Miriam Gerl (1), Iris Eberle (1), Arbnore Kabashi (1), Daphne Würzl (1), Verena Moser-Siegmeth (1), Claudia Fida (1)*

*(1) Haus der Barmherzigkeit, Vienna, Austria*

According to the latest population statistics dementia is on a path of a steady increase. Data for Austria forecasts an absolute increase from 112.600 to 262.2000 by 2050. Furthermore health and social care research into dementia has also increased with a rising number of publications and resultant practical applications for the wider community. New care concepts derived from these research studies will improve the quality of life for dementia patients and increase their self-esteem without affecting their autonomy. Hospital care providers need to consider the demands of dementia patients and facilitate new support options for these patients. Our long term care facility is situated in Vienna, the capital city of Austria. It cares for around 350 patients spread over twelve wards. Two of those wards care in particular for around 62 patients with dementia. This group of patients needs special attention to their individual requirements and needs whilst respecting their autonomy and self-determination.

This contribution provides information about excellent examples of how affirmative action can lead to a better quality of life for people affected by dementia. The concept of basal stimulation was used as a descriptive example in the first case. There is evidence in the literature that basal stimulation is suitable for people with chronic diseases. In order to illustrate this, the case of a 90 year old former university professor will be used. A short movie can testify the success of Basal (oral) Stimulation after six month of application teaching the patient how to eat independently again. The second case shows the success of biography oriented care by reference to a case of an 85 year old woman. By the use of information from her biography, her aggression was reduced with the effect that care was possible again. The third case illustrates how an analyzing case review of a 80 year old man lead to more comprehension of the care staff and subsequently a much more patient oriented humanistic care. Humanistic care is more than a benevolent and technically competent, one-sided subject-object relationship between the nurse and the patient. Care is defined here as a responsible, fathoming, mutual relationship (Paterson, Zderad 1999: 11ff). Humanistic care is to be viewed as an inner attitude, which aims to promote well-being and personal growth. The process is oriented towards the further development of human potential through interpersonal relations and responsible decision-making. Another fragment of our actions refers to the description of human basic needs according to Kitwood. Consolation, attachment, inclusion, occupation and identity are grouped around the central need to be loved and accepted, with flowing boundaries (Kitwood 2005: 122).

All three case studies testify that nurses need to approach their task consciously and deliberately and reflect this experience and describe it phenomenologically.

**Ethics, spirituality and mental health nursing care: Challenges and opportunities within inpatient rehabilitation settings**

*Cajetan Ndukwe (1)*

*(1) University of Surrey, UK*

Spirituality and spiritual care have been vital components of health care from the prehistoric times to the pre-modern era (Miner-Williams, 2006). The modern era saw the emphasis on empirical sciences which led to a gradual disappearance of spirituality in health care especially in western cultures (Hinote and Wasserman, 2016). The recent times has seen an emphasis on holistic care and spirituality seen as part of it. Hence stakeholders (RCN, 2010, NMC, 2015) in mental health care in the United Kingdom argue on the importance of offering spiritual care to patients within mental health in-patient settings as research (DiClemente, 2016) has shown the importance of spirituality and spiritual care on the recovery journey of people with mental health issues.

There is no agreed definition of spirituality within nursing care but we are going to understand spiritual care in line with the NHS Education for Scotland (2009) as the care that identify and react to the desires of the human spirit in the face of distress or infirmity and could comprise the search for meaning, sense of self, for faith support, rites or prayer or sacrament, or a sensitive listener. Given that mental health nurses spend most times with their patients among other professionals within the multi-disciplinary team (MDT), the burden of meeting patients' spiritual care needs rest on them. This is reflected in policy documents and guidelines (NMC, 2015) which raises some ethical questions.

How prepared are mental health nurses in engaging with spirituality and spiritual care issues within inpatient rehabilitation settings? What if nurses trivialise patients' spirituality and spiritual experiences as symptoms of their illness? Where do you draw a line between patients' spirituality and delusional ideations? Health care today has increasingly become scientific and often measured by outcomes, how are we going to measure spirituality outcomes within mental health inpatient rehabilitation settings? For nurses to gain competence in integrating spirituality and spiritual care into mental health care there is need for professional preparation and training. Should spirituality and spiritual care be a core module in the training of mental health nurses during their professional preparation period? Granted that there are some continuous professional development initiatives aimed at equipping nurses with skills to facilitate spirituality and spiritual care, they may not be enough in equipping nurses with the necessary skills needed for meeting the spiritual care needs of patients within mental health inpatient rehabilitation settings.

What of the environment of care in which mental health nurses practice? How adapted are the environment in supporting spirituality and spiritual care? Are there physical and mental space for nurses to engage with spirituality and spiritual care? Mental health nurses are expected to be non judgemental and unbiased observers (NMC, 2015) in building therapeutic alliance with their patients but they have their world views on spirituality and spiritual care which they bring to their profession. How would these world views influence their spirituality and spiritual care interactions with their patients? What would spirituality and spiritual care mean for a faith based, agnostic or atheist nurse?



What are the ethical boundaries of spirituality and spiritual care within mental health inpatient rehabilitation setting? Spirituality and spiritual care present some ethical challenges and opportunities within mental health inpatient rehabilitation settings and the aim of this research is to find the way forward.

#### References

- DiClemente, C. et al (2016) Consumer-Centered, Collaborative, and Comprehensive Care: The Core Essentials of Recovery-Oriented System of Care. *Journal of Addictions Nursing*, Volume 27 - Issue 2 - p 94–100.
- Hinote, P. and Wasserman, A. (2016) *Social and Behavioural Science for Health Professionals*, Lanham, MD, Rowman & Littlefield Publisher.
- Miner-Williams, D. (2006) Putting a puzzle together: making spirituality meaningful for nursing using an evolving theoretical framework. *Journal of Clinical Nursing*, Vol 15 (Issue 7), P. 811-821.
- NHS Education for Scotland (2009) *Spiritual care matters: an introductory resource for all NHS Scotland staff*, Edinburgh: NES.
- Nursing & Midwifery Council (2015) *The Code. Standards of Conduct, Performance and ethics for nurses and midwives*. Nursing & Midwifery Council, London.
- The Royal College of Nursing (RCN) (2011) *Spirituality in nursing care: a pocket guide*. London, RCN Publishers.

#### **Organisation theory and ethics: Managerialism and professionalism are they better together? An example of nursing in the UK National Health Service and virtue ethics.**

Roger Newham (1), Alistair Hewison (1)

(1) *University of Birmingham, UK*

Some recent work in organisational studies has examined the relationship between organisational theory as managerialism and professionalism from a virtue ethics perspective; suggesting that, often, they would do better working as one (Dawson, 2009). Organisations such as the UK National Health Service are provided with moral content and its action guiding or demanding force. And virtue ethics is provided with a context for the tools to action via a narrative rationality. The professional narrative is of care and equality and three strategies can be used, individually or collectively, to resist the materialist narrative since the 1980s. These are to assimilate, ignore or/and resist.

It is suggested that using this structure can be of use to nursing in two ways both of which are related to the focus on virtue ethics within nursing and illustrated in concerns such as ‘moral distress’ ‘stress’ and ‘emotional labour’. The first is to recognise that one’s focus needs to be broader than one’s character and that where, and if, managers’ ends as expressed in narratives are truly becoming vices not virtues in relation to the NHS as an organisation then such external goods and their associated ends need addressing. The external factors are not only those of the managers within the organisation but extend to policy at government level as well. Something perhaps which no individual can (nor should) do and perhaps no individual healthcare profession can or should do either. Practically this may have implications for how we think about issues such as moral distress, as well as occupational stress, and emotional labour.

The second is to do with just how complex ethical decision making in a practice such as nursing can be and what is to count as doing the right thing. Virtue ethics criterion of right as the phronimos whether with or without the idea of eudaimonia, can be used by both managerial narratives and professional narratives alike. It is not until quite extreme interpretations are put on the prominence of external goods such that nurses focus is on meeting targets of for instance efficiency rather than providing essential care it seems as though the virtues as internal goods are been driven out. But such extremes are perhaps implausible or at least the answer is clear. It is the range in-between that are of interest for knowing what to count as the right thing to feel, reason and do. Depending on the context, virtuous nurses should assimilate, ignore or resist; not suffer so extremely and individually.

### **Academic incivility: Lived experiences of Iranian nursing students**

*Alireza Nikbakht Nasrabadi (1), Mahboobe shali (1), Soodabe Joolae (2), Arpi Manookian (1)*

*(1) Tehran University of Medical Sciences, Tehran, Iran*

*(2) Nursing Care Research Center, Iran University of Medical Sciences. Iranian Academy of Medical Sciences, Tehran, Iran*

Introduction: Civility is necessary for successful teaching and learning. Academic incivility is becoming a more common and distressing problem in nursing education and it can slowly diminish a student's confidence and interfere with learning and academic inquiry. It is imperative that nurse educators understand the phenomenon of incivility among nursing students and begin to formulate probable solutions.

Aim: The aim of this study was to explore the lived experiences of incivility in among a group of Iranian undergraduate nursing students.

Method: Data were collected through semi-structured interviews and analyzed using Colaizzi's method of data analysis. Participants were 14 nursing students who had faced with different kinds of incivility experiences. Data were collected through individual and face to face interview. The audiotapes were transcribed and analyzed for common themes that represented the participants' experiences.

Results: Students identified several faculty behaviors that they perceived to be uncivil, including: low patience, rude condescending remarks, poor teaching style, , canceling class without previous coordination, being unprepared for class, showing disinterest in the students or class, and not being available outside of class, and finally challenge other faculty's knowledge and credibility.

Conclusion: This study provided insights into the lived experiences of nursing students related to incivility in the field of education. Incivility encompasses a variety of undesirable behaviors that are actually occurring in nursing education. Nursing Faculties and nurse educators have the responsibility to be aware of the prevalence of incivility, assess for its occurrence, and implement strategies for eliminate that.

**Impact of ethical climate and ethical leadership on moral distress among nurses in South Korea**

Younjae Oh (1)

(1) *Department of Nursing, Hallym University, South Korea*

**Background:** Moral distress experienced by numerous nurses is caused by situational constraints when confronted with ethical problems. To alleviate moral distress among nurses, nursing scholars mainly emphasize positive ethical climate which is perceived by nurses as a process and a practice ethically handled in nursing environment. In this context, ethical climate of the work setting can be definitely associated with leadership style or leader's ethical behaviors. That is, chief or head nurses as managers have a primary role in shaping ethical climate. Their ethical leadership behaviors can reduce moral distress in nurses by sharing their nurses' ethical concerns or seeking appropriate resolution. However, there is lack of research regarding the association among ethical climate, ethical leadership, and moral distress and the impact of ethical climate and ethical leadership on moral distress among nurses.

**Purpose:** The purpose of this study was to investigate the relationship among ethical climate, ethical leadership and moral distress and the impact of ethical climate and ethical leadership on moral distress among nurses in hospital settings.

**Methods:** A descriptive and correlational research was adopted by registered nurses from 4 general hospitals in South Korea. A convenience sample of 222 registered nurses was recruited in July to September, 2016. The size of samples was calculated by using the G\*power Program (3.1 version) ( $p=0.05$ , effect size=1.5, power=0.80). The Korean versions of valid and reliable instruments were employed to measure the levels of ethical climate, ethical leadership and moral distress.

**Results:** Moral distress was negatively correlated with ethical climate and ethical leadership. That is, moral distress is higher for nurses who had a less ethical perception toward ethical climate and their managers' leadership. As for subdomains of ethical climate, the association between "ethical perception regarding manager" and "moral distress" was significantly the strongest ( $r=-0.37$ ,  $p<0.001$ ). The nurses who perceived their managers to be less honest and trustworthy felt stronger moral distress. As for subdomains of ethical leadership, the association between "ethical guidance leadership" and "moral distress" was significantly the strongest ( $r=-0.35$ ,  $p<0.001$ ). When managers had less consistent ethical guidance, the nurses felt stronger moral distress. Furthermore, the "ethical perception regarding manager" subdomain of ethical climate ( $\beta=-0.36$ ,  $p=0.001$ ) and the "ethical guidance" subdomain of ethical leadership ( $\beta=-0.27$ ,  $p=0.003$ ) were significant influential factors on moral distress.

**Conclusions:** Ethical climate and ethical leadership had impact on moral distress among nurses. Particularly, the ethical role of the manager was a crucial factor to predict moral distress. Therefore, nursing leaders should demonstrate ethical attitudes and behaviors based on clear ethical standards and healthcare organizations should take responsibility for creating high ethical working environment as well in order to lessen moral distress in nurses.

## **Online ethics consultation for mental health and psychiatry in Japan**

*Kayoko Ohnishi (1), Kazuyo Kitaoka (2), Takashi Yoshiike (3)*

*(1) Konan Women's University, Kobe City, Japan*

*(2) Kanazawa University, Japan*

*(3) Osaka University of Human Sciences, Japan*

Many institutions establish clinical ethics committees to address ethical issues or various problems in clinical settings. In Japan, however, many hospitals, especially psychiatric hospitals, still have neither clinical ethics committees nor clinical ethics consultants. Many ethical issues arise in mental health and psychiatric settings, and mental health nurses with less authority are often stumped not only by ethical dilemmas, but also by the amount of moral distress; that is, they know what is right, but cannot pursue this course due to institutional or other obstacles. In these instances, nurses require someone who can serve as a consultant as well as encourage them to do what they believe is right.

The purpose of this presentation is to describe our online ethics consultation system and its observed outcomes.

In June 2014, we established a website dedicated to ethics consultations for mental health and psychiatric care. Visitors to the website can contact us and receive an anonymous consultation regarding their ethical dilemma, at no charge. Our 13 consultants include mental health nurses, psychiatrists, psycho-social workers, and lawyers. Several consultants with different professions are assigned to one case. The head of the committee [KO] summarizes the consultant views and sends these to the consultee. After the process is complete, we send a brief questionnaire to the consultees, asking about their satisfaction with the consultation, the usefulness of our responses, and whether the responses were provided in a timely manner.

For the first two and a half years since establishing the website, approximately 2900 visitors accessed the website, with eight consultees. Of these, four were psychiatric nurses, two were psychiatrists, and two were, surprisingly, service users. The response time ranged from one day to 14 days, and depended on the urgency indicated by the consultees. Our answers to a summarized version of the original questions were displayed on the website with consultee permission.

Constraint was the most common topic for consultation. Some topics concerned potentially illegal issues; specifically, all inpatients were prohibited from using the telephone after 21:00, and nurses kept all inpatient telephone cards, which prevented the patients from using the phone. Some were ethical dilemmas; e.g., should inpatients with the flu be secluded when they refuse to stay in their room, and instead are choosing to roam the dayroom? Two cases potentially involved severe violations of human rights, one of which was from a staff member working in a facility for mentally retarded children, and the other from an ex-inpatient.

Only three consultees responded to the questionnaire about the website and its services. All respondents reported that they were satisfied with their consultation, and that the response time was satisfactory. However, we could not examine the efficacy of the system due to the low number of consultations. As we move forward, we hope to increase the awareness of our website by informing other mental health professionals.

## **Ethical professional communication and social media**

Douglas P. Olsen (1)

(1) *Michigan State University College of Nursing, USA*

The potential for unprofessional communication and the damage it can cause are greatly magnified by the reach of social media combined with its blurring of public and private communications. This presentation will review the ethical basis for public advocacy by nurses, review the risk of unprofessional communication posed by social media, and suggest standards for professional communications made through social media. The case of a nurse found guilty of professional misconduct by the Saskatchewan Registered Nurses' Association in Canada will be used to illustrate these issues.

The public benefits when nurses add their voice to discourse regarding healthcare issues. Nurses speak authoritatively on scientific and policy matters, but more critically they add the experiential expertise of intimate contact with the sick, and the dying as well as healthy patients. Codes of ethics from both the American Nurses Association and International Council of Nurses are clear that nurses have an obligation to advocate for population health and social justice. Society legitimizes and empowers nursing through licensure and in return expects value in the form of quality nursing care which includes thoughtful, knowledgeable contribution to public healthcare discourse and policy formation. Public communication identified as informed by nursing knowledge, that is when speaking "as a nurse," must conform to professional standards. Unprofessional communication is poor nursing care; it violates nurses' obligation to the public and can damage the public's trust in nurses and harm society.

Suggestions include standards for content such as commenting on clinical effect, service delivery and protection of dignity and privacy, as well as advice about the process of posting to help ensure that commentary is made in an ethical manner.

## **Method of estimation of expectation and satisfaction with dignity of patients with dementia: Examining the feasibility of the iPDS as a proxy estimation of patient dignity**

Katsumasa Ota (1), Eriko Otake (2), Yukari Niimi (3), Chikako Sone (4), Satoko Yamada (5), Jukai Maeda (6), Masami Matsuda (7)

(1) *Nagoya University, Japan*

(2) *National College of Nursing, Japan*

(3) *Seirei Christopher University, Japan*

(4) *Nagano College of Nursing, Japan*

(5) *Japanese Red Cross Toyota College of Nursing, Japan*

(6) *Tokyo Ariake University of Medical and Health Sciences, Japan*

(7) *Tokyo Kasei Gakuin University, Japan*

Background: In most countries, the proportion of people aged over 60 years is growing fast, resulting in an increase in the number of patients with Dementia. Many studies show that there are several problems with nursing care for patients with Dementia, and often their dignity may not be preserved

appropriately. For example, different kinds of abuse use of physical and chemical restraint for preventing falls and safety during the administration of intravenous drips, and rude verbal communication. Even if nurses intend to protect patients' dignity, it is difficult for them to know what patients expect in and to what extent they are satisfied with daily care. Therefore, we explored a method to estimate their expectations and satisfaction based on proxy answers from family members of patients or nurses instead of the patients themselves.

**Purpose and Measures:** The purpose of our study was to develop a questionnaire on patient dignity for nurses and family members of patients, and to develop a method to estimate the expectation and satisfaction of Dementia patients based on these proxy answers. We first examined the feasibility of the proxy questionnaire of the international Patient Dignity Scale (iPDS) that was originally developed to measure inpatients' expectations and satisfaction with dignity, based on interviews with nurses and patients' family members. Then we revised and modified its questions based on the extracted comments by examining its content validity using the Content Validity Index (CVI). Our study was conducted after receiving IRB permission.

**Results and Discussion:** Twelve nurses with an average clinical experience of 14.3 years in four hospitals, and seven family members of patients in Japan participated in the first step of this study from April 2015 to March 2016. Ten out of the twelve nurses affirmatively answered that it was possible or partially possible to estimate patients' expectation and satisfaction using the iPDS or the modified iPDS, whereas two nurses replied that it was impossible to estimate them. We extracted 66 codes from the interviews (average duration: 26 minutes). Twenty-four of these codes referred to the basis of estimation of patients' expectations and satisfaction with dignity in daily care; for sentences such as "I usually consider patients' thought and feelings based on their expressions or gestures," actions like "movement of hand or foot and nervous jiggling of their legs," and personality characteristics of the patient before he/she suffered from Dementia. On the other hand, 22 codes referred to difficulties in estimation because of lack of distinct features and differences in the degree of the symptoms of dementia, especially with reference to the estimation of satisfaction. We will report the rest of codes and the responses of family members in our presentation. We modified the iPDS and reconstructed a questionnaire for nurses in charge or family members with 30 questions regarding Dementia patients' expectations and 23 questions regarding their satisfaction. Using this reconstructed questionnaire, we are now conducting a nationwide survey in Japan.

This study was supported by Grant-in-Aid for Scientific Research (B): No. 26293445.

### **Legal regulation and disciplinary actions among nurses: An integrative review**

***Oili Papinaho** (1)(2), Mari Kangasniemi (1), Arja Häggman-Laitila (1)*

*(1) (1)University of Eastern Finland, Kuopio, Finland*

*(2) (2)Oulu University Hospital, Oulu, Finland*

**Background:** Many different types of errors in health care made by nurses can be detected and the sanctions and disciplinary actions by nursing boards are important to identify. There is little earlier literature of this subject.

**Aim:** The aim of this study was to describe legal regulation and disciplinary actions against nurses, to identify disciplined nurses and nursing errors by an integrative review.

**Method:** An integrative review was a research method to describe legal regulation and to identify the disciplined nurses, nursing errors and disciplinary actions among nurses according earlier literature. Systematic literature searched were conducted in November 2016 in four electronic databases, CINAHL, PubMed, Scopus and Web of Science finding scientific papers in English during 2006-2016. Both qualitative and quantitative studies were included. Manual search of references of the full-text papers and selected journals yielded five more papers making final total 20 selected papers. Papers were analysed by content analysis.

**Results:** Twenty studies were analysed and categorised. The preliminary results of the data compose three categories: legislation in nursing regulation, description of the disciplinary actions against nurses and description of the nursing errors. At present, the data analysis is under way and the final results will be ready and described in a conference presentation.

**Conclusion:** Results of this study produce identification of legal regulation of the nurses' professional rights and disciplinary actions against nurses.

### **Transitioning from the clinical to the ethical judgement: A dialectical approach to ethics education in advanced practice nursing**

*Pierre Pariseau-Legault (1), Melisa Lallier (1)*

*(1) Université du Québec en Outaouais, Canada*

Over the last decade, the nursing discipline has quickly evolved, leading to an observable gain in the autonomy of everyday practice. Around the world, nurses are taking distance from the technical role historically attributed to their profession. Even if this situation contributes to the recognition of their moral agency, ethics is often perceived by students as distant from their clinical realities. The pragmatic stance of nursing practice and the abstract fundamentals of ethics are often placed in a counter-productive and dualistic position. There is therefore a responsibility of educators to illustrate how ethics can, in fact, enlighten and optimize clinical reasoning.

In this paper, the authors discuss about their pedagogical encounter, which led to the development of an ethical training curriculum for advanced nursing practice in Quebec, Canada. The first author is a registered nurse and assistant professor, with a specialised background in health law, ethics and policy. He actually teaches undergraduate and graduate nursing courses in ethics, health law and mental health. The second author is a nurse practitioner in primary care and also a lecturer for graduate courses in advanced nursing practice. Both authors are actively engaged in the education of the next generation of registered and advanced practice nurses. In this context, they accepted to exchange about their backgrounds in order to construct an ethical training that would be more adapted to the recent evolution of nursing practice.

Inspired by symbolic interactionism theory, the authors reflect about how their encounter sustained a dialectical approach to nursing ethics. This approach created a space of dialogue where clinical and ethical reasoning were put to contribution to achieve a common objective. This objective was to

contribute to the development of an ethical training that can consolidate moral integrity and close the perceived gap between clinical judgement and ethical deliberation. In order to achieve this objective, the authors constructed case studies inspired by practice, in which the clinical outcomes were dependent of a sustained ethical deliberation.

Taking the question of autonomy and consent to care as a core example, this paper illustrates how this dialectical approach influenced the final structure of the ethical training. It proposes a pedagogical curriculum by which the interactions between the autonomy principle and the socio-legal object of “consent to care” are clinically appraised and ethically discussed by students. This process allows insightful discussions on the assessment of patient’s competence to consent to care, but also about the respect for persons, the difference between individual and relational autonomy and associated relevant ethical issues. The authors suggest that this pedagogical approach has the potential to optimize the consolidation of deliberative competencies among nurses and to highlight the ethical components fundamentals to their clinical judgment. Implication and potential challenges for ethics education in nursing will also be discussed.

### **The relationship between ‘ethical audit’ in care organisations and the ethics of care**

David Perry (1)

(1) *University of Surrey, UK*

‘Social care’ is the name given to all care provided to people in the UK other than by the NHS (usually known as ‘health care’) or private (non NHS) health providers. By far the largest group in receipt of social care is older people (other groups include children, people with mental health problems and learning difficulties).

In 2013, Skills for Care estimated the total spend on social care to be c £20bn per year. In England the total number of providers was 9,300 (residential care) and 12,800 (non residential - domiciliary, day care etc). Most social care is paid for by local NHS and Local Government organisations (over 200). Forty or 50% of care for older people in care homes is self pay - with wide variations from region to region. In recent times, there has been a good deal of attention to unethical practice in social care and to the need for ethics education (see, for example, the RIPE project - <http://www.surrey.ac.uk/fhms/research/centres/ICE/>).

The presentation explores some of the ethical issues that arise for commissioners, providers, regulators and investors during what is regularly referred to as a period of social care ‘crisis’.

The presenter will draw on insights from the USA relating to an ‘ethical audit’ approach. Many US companies have joined formal programmes to improve and assess their ethical performance using this approach. There will be discussion of the relationship between an ‘ethical audit’ approach and care ethics and recommendations made as to how this approach might be operationalized to good effect in the UK social care sector.



**Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and hematology care\***

*Mona Pettersson (1), Mariann Hedström (1), Anna T. Höglund (1)*

*(1) Centre for Research Ethics and Bioethics, Uppsala University, Sweden*

Background: Within oncology and hematology care, patients are sometimes considered to have such a poor prognosis that they can receive a do not resuscitate order from the physician responsible, stipulating that neither basic nor advanced coronary pulmonary rescue be performed in the event of a cardiac arrest. Studies on do not resuscitate decisions within oncology and hematology units, focusing on the specific role of the nurse in relation to these decisions, are scarce.

Objective: The aim of this study was to investigate hematology and oncology nurses' experiences and perceptions of do not resuscitate orders, in order to achieve a deeper understanding of the nurses' specific role in these decisions.

Research design: A qualitative, descriptive methodology with individual semi-structured interviews was used.

Participants and research context: A total of 15 nurses from eight hematology/oncology wards in four hospitals in Sweden were interviewed individually.

Ethical considerations: The research followed international guidelines for empirical research, as outlined in the Helsinki Declaration. In accordance with national regulations, an ethical review was not required for this study.

Findings: The nurses strived for good nursing care in end-of-life care and DNR decisions through balancing harms and goods and observing integrity and quality of life as important values. Experienced hindrances for good care were unclear and poorly documented decisions, uninformed patients and relatives, and disagreements among the caregivers and family. The nurses expressed a need for an ongoing ethical discussion on do not resuscitate decisions, including all concerned parties.

Conclusion: In order to provide good nursing care in end-of-life care and DNR decisions, nurses need clear and well-documented do not resuscitate orders, and patients and relatives need to be well informed and included in the decisions. To increase the understanding for each other's opinions within the medical team, regular ethical discussions are required.

---

\*Pettersson, M., Hedstrom, M. & Hoglund, A. T. (2014). Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and hematology care. *Nursing Ethics* 21(8): 902-915.

### **Inter-professional teamwork and reflective practice in 55 acute geriatric units in Belgium**

*Ruth Piers (1), Karen Versluys (1), Johan Devoghel (2), André Vyt (3), Nele Van Den Noortgate (1)*

*(1) Department of Geriatric Medicine, Ghent University Hospital, Ghent, Belgium*

*(2) Department of Geriatric Medicine, St Jan Hospital Bruges, Bruges, Belgium*

*(3) Artevelde University College & University of Ghent, Ghent, Belgium*

Background: Inter-professional teamwork (ITW) and reflective practice is linked to quality of care and patient advocacy, outcomes highly valued in geriatric medicine. Yet, research in acute geriatric units (AGUs) is lacking.

Method: Perceptions of ITW and reflective practice among team members of 55 AGUs in Belgium were measured using a survey covering 6 areas: 1) collaborative practice and experience; 2) managerial coaching and open team culture; 3) shared reflection and decision-making; 4) patient files' facilitating teamwork; 5) members' belief in the power of teamwork; 6) members' comfort to report incidents. Comparisons between professions and clusters are performed by ANOVAs. Cluster analysis was used to determine types of ITW.

Results: Of 890 respondents, 71% were nursing professionals, 20% paramedical professionals and 5% physicians, 4% were logistic and administrative workers. Overall response rate was 60% (66% among nursing professionals, 53% among paramedics and 40% among physicians). More than 70% of team members scored high on ITW competences, consultation, experiences, meetings, management and results. Less than 50 % scored high items concerning shared reflection and decision-making, reporting incidents from a colleague and patient files facilitating ITW. Nurses in this study rated shared reflection and decision-making ( $p=0,001$ ) and belief in the power of ITW ( $p<0,001$ ) lower compared to physicians of the same AGUs. Using the mean team score on each of the 6 areas, hierarchical cluster analysis and consequently scree plot analysis identified 4 clusters that differed significantly in all the areas ( $p<0,001$ ).

Conclusion: ITW in AGUs is satisfactory, however shared reflection and decision-making needs improvement. The identification of 4 types of ITW can trigger team-oriented discussions and a dynamic view of team development.

### **Good human life in assisted living for older people: What the residents are able to do and be**

*Jari Pirhonen (1)*

*(1) University of Tampere, Finland*

Assisted living as a form of elderly care carries the promise of providing people with less institutional living arrangements, better chances to maintain more individualistic life-styles, and better prerequisites for older peoples' autonomy. Similarly in Finland as in the rest of the West, person-centered care has become the new watchword for high quality assisted living services for older people. Person-centeredness entails service provision being guided by individual's values and desires, aiming to secure the individual's independence. Since such an independence-emphasizing perception of the

clientele in assisted living might be a bit misleading, the aim of this research was to reassess the substance of person-centeredness.

The research question then became how older people could perform their personhood. Based on the Capabilities Approach, the question sharpened as what the residents were able to do and be while residing in assisted living. Residents' doings were approached through their autonomy and agency, and beings through their chances to become recognized as persons and reach affiliation in their living surroundings.

Ethnographical research frame was chosen to study residents' autonomy, agency, recognition, and affiliation in their mundane living surroundings. Participant observation was conducted in two elderly care facilities in southern Finland in 2013. In addition, residents of an assisted living facility were interviewed in 2014.

Residents' autonomy was found to be essentially relational. Residents' remaining functional abilities had a positive effect on autonomy but did not dictate it. Residents sustained their feeling of autonomy for example by utilizing people outside the facility, compensating age-based losses in multiple ways, and emphasizing the possibilities to act instead of actual acting.

Due to hampering functional abilities, residents' agency was not action-oriented but encompassed being as well as doing. The major finding was that instead of traditional agency, we could speak about agentic spaces in assisted living. Agentic spaces were created when residents' capabilities and motivations met the affordances of the surrounding.

Residents got recognized and misrecognized as persons for several reasons connected to the resourcing of care, the daily routines of the facility, and the staff's attitudes. Major reasons why residents were not recognized as persons were residents' invisibility, staff timetables, standard treatment, dominant role of documents, and shifting responsibility. On the other hand, residents were recognized by offering them privacy, giving them opportunity to continue life-long habits, joking and debating with them, and putting an active emphasis on their wishes.

Residents' affiliation was studied by ruptures in it, i.e. by feelings of isolation, which were based on multiple factors ranging from residents' life histories and their personalities to resourcing of care and working culture of the facility. Residents' affiliation in a facility was based on their chances to bond with people on site on the one hand, and people outside the facility on the other hand.

### **Legal and ethical issues in geriatric care: A systematic literature review**

*Nertila Podgorica (1), Magdalena Flatscher-Thöni (2), Michael Ganner (3)*

*(1) UMIT - University for Health Sciences, Medical Informatics and Technology, Austria; University of Shkodra, Albania*

*(2) UMIT - University for Health Sciences, Medical Informatics and Technology, Austria*

*(3) University of Innsbruck, Austria*

As society is aging, it is observable that elderly people have problems and needs that require attention and care from the family, health care practitioners, health care systems, as well as societies to promote their health, well-being, recovery from illness or disability, and sustaining a healthy life (Clement,

2013). This vulnerable group of society, namely elderly people, requires an individual health care, which should not only focus on the medical circumstances but should also include ethical and legal perspectives when it comes to geriatric care.

To lay the groundwork for a better understanding and the improvement of geriatric care, focusing on ethical and legal issues, we conducted a systematic literature review of studies published between 2000 and 2015 that reported ethical and legal issues in geriatric care and provided qualitative and quantitative data. We used MEDLINE (PubMed), CINAHL, EthicShare, and Google Scholar and specific keywords, e.g., ethics, bioethics, law or legislation, or geriatric care and elderly care, to select the relevant articles. This process revealed 50 relevant publications.

Our results show that most of the studies (22 out of 50) work with qualitative approaches, e.g., grounded theory or participatory action research, using instruments such as interviews, focus group interviews, or clinical cases, leading to a qualitative data situations. Additionally, most of the studies focus on ethical issues more than on legal issues, sometimes describing the ethical and legal issues in an interfered way. The current results show that legal issues focus on patients' rights, advanced directives, decision-making issues, elderly rights, treatment/nutrition, and the legal dilemma, autonomy as a human right, professional liability, and informed consent. Ethical issues focus on respect for older people's autonomy; respect for elderly needs, wishes, and values; and respect for elderly decision-making. The ethical principle of beneficence includes benefits and costs, preventing harm, patients' rights, fidelity, health care services and systems, staff experience, and communication within the team, the elderly, and their relatives. Different ethical dilemmas and conflicts between the ethical principles are important ethical issues from the health care practitioners', families', and patients' point of view. The review at hand is aiming at revealing the most relevant, ethical, and legal issues of geriatric care on an international level and portray a picture of challenges faced by health care practitioners, elderly people (patients), and relatives related to geriatric care. The results of our review can help healthcare practitioners, as well as policy makers, to set priorities for future education and support for people working in the field of geriatric care.

### **Case study: Euthanasia in Colombia**

*Yolanda M. Guerra Post (1), Maria Margarita Tirado (2)*

*(1) University Militar Nueva Granada, Facultad de Educación y Humanidades, Bogota, Colombia*

*(2) University Militar Nueva Granada, Law School, Bogota, Colombia*

Colombia is the first country of the world that in May of 1997 decriminalized euthanasia. However, although the subject of euthanasia is highly controversial, the discussion for over 20 years in Colombia, has focused not only in the convenience of euthanasia in Colombian society, but also and more relevantly, on whether or not it is legal the procedure that decriminalized euthanasia: a decision of the Supreme Court, instead of a formal law created by the Congress. Considering that Colombia is a legalist country where the codes and the Constitution are in the first position of the pyramidal authority of norms in Colombia, unlike the United States for instance, where the jurisprudence has a relevant power in the legal system; ¿does a sentence have the same power and cause the same effect of a formally promulgated law made by Congress? On the contrary, does a decree have the power to endure this practice and to decriminalize an action that is, according to the Criminal Colombian Code,

still a crime? Has the Colombian Supreme Court overlapped the legislative branch and crossed the frontiers of its responsibilities by creating laws for which it has no constitutional authority to do so? How does this affect the practice of euthanasia by doctors and institutions in Colombia?

Central research question to be explored: This is an ethical dilemma that also crosses the frontier of legality, where the cause of the confusion is created by the authorities of Colombia. One of the fundamental duties of the government of a country is to provide certainty, at least legal certainty, for the citizens to behave accordingly. This is not the case, in Colombia, is the legal system, the judges and the government the main cause of confusion. What is the consequence in the application of euthanasia in Colombia, considering that it was decriminalized through a sentence instead of a formal law? Have euthanasia cases increased in Colombia due to this jurisprudence? Have medical doctors who applied euthanasia been prosecuted because of the lack of formalization of the decriminalization in the Colombian law? How can this gap between jurisprudence and law be filled in order to offer juridical and bio political certainty to the Colombian people regarding the treatment of euthanasia in Colombia?

The methodology used complies with the empirical analytical approach of the research, interviews to medical doctors were done, as well as to care services people and to the families of patients who died through euthanasia, whether active or passive. Also, jurisprudence and law were revised to see if doctors who have applied euthanasia have been prosecuted.

Content of the presentation: Antecedents of euthanasia in the world; Content of the jurisprudence that decriminalized euthanasia in Colombia; The objections of the four Supreme Court judges that made the decision in a panel of nine judges; The practice of euthanasia in Colombia; The gap between law and jurisprudence; and conclusions.

### **Dignity of Residents Living in Nursing Homes: Experiences of Family Caregivers**

*Maj-Britt Råholm (1), Britt Lillestø (2), Vibeke Lohne (3), Synnøve Caspari (3), Berit Sæteren (3), Anne Kari Tolo Heggstad (3), Trygve Aasgaard (3), Lillemor Lindwall (4), Arne Rehnsfeldt (5), Bente Høy (6), Åshild Slettebø (7), Dagfinn Nåden (3)*

*(1) Western Norway University of Applied Sciences, Førde, Norway*

*(2) Nord University, Bodø, Norway*

*(3) Oslo and Akershus University College of Applied Sciences, Oslo, Norway*

*(4) Karlstad University, Karlstad, Sweden*

*(5) Western Norway University of Applied Sciences, Stord, Norway*

*(6) VIA University College, Aarhus, Denmark*

*(7) University of Agder, Grimstad, Norway*

This study describes different perspectives of dignity in the care of residents experienced by family caregivers. Both patients and family caregivers express existential concerns about dignity in care, but differences between these experiences are out of phase with each other. Individual interviews with 28 family caregivers were conducted between January and February 2010. Data were analyzed using the philosophical hermeneutic method; reflection, preunderstanding, interpretation, and new understanding played an important role in the ongoing process of analysis. The findings describe the

family caregivers' experiences in daily life to receive dignifying care for their relatives and how struggling with their own vulnerability opens up the existential dimension of dignity.

### **Moral distress in nursing teachers: Advances of conceptual framework**

*Flávia Regina Souza Ramos (1), Alessandra Mendes de Barros (1), Dulcinéia Ghizoni Schneider (1), Maria José Menezes Brito (2), Heloíza Maria Siqueira Rennó (3), Luciana Ramos Silveira (1), Mara Ambrosina Vargas*

*(1) Federal University of Santa Catarina, Brazil*

*(2) Federal University of Minas Gerais, Brazil*

*(3) Federal University of São João del-Rei, Brazil*

The moral distress represents an important problem in professional nursing education or practice and has been explored in different countries and contexts of nursing. Pioneering studies substantiate moral distress as the phenomenon in which the nurse is aware of the morally correct action but is unable to act according to his/her moral premises or knowledge; caused by institutional or personal obstacles and conflicts; that results into pain, anguish, impotence, and conducts morally inappropriate that may damage the quality of care. Several researches on the topic, including the construction of the scale of moral distress of Brazilian nurses, are being developed by group of nursing researchers. It is believed that frameworks and theoretical models need strengthening and expansion to support studies for the current research stage, assuming the insufficiency and limitations in the use of the moral distress concept or strictly descriptive and psychometric approaches. The first step was to propose conceptual elements for the analysis of moral distress as a process that articulates other concepts or moments of the moral experience, such as moral sensitivity, moral deliberation and others, profoundly involved in the development of moral competencies and with the construction process of the ethical subject. One of the studies part of the project was aimed at analyzing the process of moral distress in the practice of nurses teaching higher education in nursing, and also knowing the strategies of deliberation related to moral distress in their work. Twelve teachers from three undergraduate courses in nursing participated in three rounds of an adapted Delphi method, drafting and validating the constructs. Based on the results, the conceptual framework proposed was updated and revised for the specificity reality of the teaching environment, contributing to the understanding of elements that participate in the process of moral distress. These elements were associated with relationships with students (indifference, disregard, judgments and bad attitudes, fraud), the conflicts concerning the driving and pedagogical collective decisions and especially, the relationship between the faculty itself or in the set of practice (curricular internship). The moral suffering at the work environment can lead to the development of strategies that promote moral deliberation by individual and collective actions, including the defense of principles and dialogue; at the same time can produce compensatory mechanisms, preservation and not personal involvement. Corroborating the conceptual framework adopted, investigate the triggers of the moral distress, integrate the experience of the self, show an expression of their most productive face, that is, in the construction of strategies of confrontation, deliberation and formation of the ethical subject.

FUNDING STATEMENT: - National Council for Scientific and Technological Development (CNPq/Brazil);  
- Coordination for the Improvement of Higher Education (CAPES/Brazil).

**Nurses' perspective on challenges in next of kin relationships in end-of-life care: A critical study based on feminist ethics.**

*Ellen Ramvi (1), Venke Irene Ueland (1)*

*(1) University of Stavanger, Norway*

For the experience of end-of-life care to be 'good' many ethical challenges in various relationships have to be resolved. In this presentation, we focus on challenges in the nurse–next of kin relationship. Little is known about difficulties in this relationship, when the next of kin are seen as separate from the patient.

We ask, from the perspective of nurses: What are the ethical challenges in relation to next of kin in end-of-life care?

We used a critical qualitative research design, based on four focus group interviews. A total of 22 registered nurses enrolled on an Oncology nursing specialisation programme with experience from end-of-life care from various practice areas participated.

The study was approved by the Norwegian Social Science Data Service, Bergen, Norway, project number 41109, and signed informed consent obtained from the participants before the focus groups began.

Two descriptive themes emerged from the inductive analysis: 'A feeling of mistrust, control and rejection' and 'Being between hope and denial of next of kin and the desire of the patient to die when the time is up'. Deductive reinterpretation of data (in the light of moral distress from a Feminist ethics perspective) has made visible the constraints that certain relations with next of kin in end-of-life care lay upon the nurses' moral identity, the relationship and their responsibility. We discuss how these constraints have political and societal dimensions, as well as personal and relational ones.

We can conclude that there is complex moral distress related to the nurse–next of kin relationship, which calls for ethical reflections regarding these relationships within end-of-life care.

**Creating the theoretical construction of stroke patients' dignity realization**

*Sunna Rannikko (1), Minna Stolt (1), Riitta Suhonen (1)(2)(3), Helena Leino-Kilpi (1)(2)*

*(1) University of Turku, Department of Nursing Science, Finland*

*(2) The Hospital District of Southwest Finland*

*(3) City of Turku, Welfare Division, Finland*

BACKGROUND: Stroke patients are worldwide a common patient group and stroke is the second leading cause of death. Of the survivors, many are temporarily or permanently disabled. The effects of stroke are comprehensive including impact on cognition, function, self-concept, health perception, role identity and relationships. Thus stroke requires enormous adjustment from the patient to the new situation and the adjustment may require a rather long time period. From the ethics point of view, as

with other vulnerable patient groups, stroke patients' dignity is crucial to be protected. However, study concerning stroke patients' dignity is scarce. As patient dignity is related to for example enhance patient outcomes and higher satisfaction with health care, dignity of this special patient group deserves more study. Earlier studies of dignity in hospital environment from patients' point of view are concentrating on explaining the concept of dignity and representing factors promoting and reducing dignity. However, this particular study has a different approach to dignity as the realization of stroke patients' dignity in hospital environment is under investigation.

**AIM:** The aim of the study was to create a theoretical construct to describe stroke patients' dignity realization in hospital care. The goal was by the description to enable health care personnel to understand stroke patients' dignity realization.

**METHODS:** The data were collected interviewing 16 stroke patients in the year 2015. Semi-structured interviews were conducted during patients' hospital care. The data were analyzed using the constant comparison of Grounded Theory. The participants varied from their background factors giving rich data for the theory construction.

**RESULTS:** The theory construction reached for describing stroke patients' lived life in the dignity realization. On that basis, the 'Theory of Realization of Stroke Patients' Dignity in Hospital Care' was created. At the very beginning of the theory construction it was obvious dignity realization occurring in this new situation as part of stroke patient's life not separated from history and previous experiences. Further, the theory construction exposed patient's individual understanding about dignity lying underneath the dignity realization. In the creating process, the theory started to reveal some similarities with previous studies concerning patient dignity in hospital care. However, the created construction as a whole is new.

**CONCLUSION:** The constructed theory provides a new frame for the health care personnel to understand the ethical principle of dignity from the patient's viewpoint. Further, this may be used in the development of the ethically high level care. By this, enhanced patient outcomes and higher satisfaction with health care may be reached. In the field of research, the constructed theory deepens the knowledge of dignity in hospital environment by giving a different approach to the topic. It also enlarges the basis of stroke patients' ethical issues and provides a better understanding for future studies. Still, as approaching the ethical principle of dignity from the fresh viewpoint of realization, the topic needs more study.



## **Ethical aspects of nursing with chronic non-cancer pain patients**

*Jaroslava Raudenska (1), Alena Javurkova (2)*

*(1) Department of Nursing, 2<sup>nd</sup> Faculty of Medicine, Charles University and Motol University Hospital, Prague, the Czech Republic and Department of Clinical Psychology, Motol University Hospital, Prague, the Czech Republic*

*(2) Department of Nursing, 2<sup>nd</sup> Faculty of Medicine, Charles University and Motol University Hospital, Prague, the Czech Republic and Department of Clinical Psychology, KV University Hospital, Prague, the Czech Republic*

We would like to focus on ethical problems and issues of the nursing with chronic non-cancer pain patients. The first part of report will describe the term of the ethics; subsequently, we will define medical and nursing ethics and related necessity of teaching the ethics in the course of education of nurses specialized in pain therapy. Furthermore, we would like to specify ethical values and ethical decision-making applied in the treatment of chronic non-cancer pain. Some ethical dilemmas are offered from the point of view of the nurse and the patient, as well as ethical principles of chronic non-cancer pain therapy. All dilemmas are intertwined. The purpose of this report is to provide some ethical views, considerations, dilemmas and stimuli that may help to effectively treat patients with chronic non-cancer pain with honour. The therapy of pain on a high professional level, but also empathetic, legal therapy focused on ethical aspects will have a significantly positive impact on therapy success in the patient with chronic non-cancer pain. The report also emphasizes that individual ethical opinions of every patient will also reflect how the patient responds to various types of pain therapy, how he or she cooperates with the team (nurses included) and adheres to therapeutic recommendations, and what kind of benefit it will have for him or her in terms of understanding the sense of life even if associated with suffering and chronic non-cancer pain.

## **Telling the truth or withholding it: Ethical issues in end-of-life care of patients dying due to unexpected sudden death from stroke**

*Asa Rejnö (1)*

*(1) University West, Skaraborg Hospital Skövde, Sweden*

Background: Ethical problems are especially evident in the end of life and thus also in end-of-life care. Since stroke is the second most common cause of death globally, and mortality in the acute phase is considerable, stroke team members are frequently confronted with such problems. Patients dying due to acute stroke often have reduced consciousness and thereby a limited ability both to convey their needs and to make decisions about their own care. They accordingly could be described as 'incompetent' as decision makers and thus in a vulnerable situation and in need of protection of their dignity. Next of kin can contribute valuable information about their loved one and often act as proxies in these situations, despite the fact that they themselves might be in shock and in need of support.

Methods: The aim of the study was to deepen the understanding of stroke team members reasoning about truth-telling and truthfulness when caring for patients dying from acute stroke and often with reduced consciousness. Four physicians, seven registered nurses and four enrolled nurses, all in all four males and eleven females, working at acute- and rehabilitative stroke units at two hospitals in Sweden

participated. The interviews were analysed with combined deductive and inductive content analysis and resulted in two categories and five subcategories.

Results: The main findings were the team members' dynamic movement between the categories 'truth above all' with the subcategories 'a value in itself' and 'to establish trust' and the category 'hide truth to protect' and its subcategories 'not add extra burden on the sorrow', 'awaiting the timely moment' and 'not being the messenger of bad news'. Not to do harm could be described as a common thread, connecting all the categories and subcategories in a united theme. The stroke team members' honoured honesty high and held it as reason for always telling the truth without embellishing, with the argument of truth as common morality. Truth was however also showed to be viewed as harmful. The team members stated they commonly could hide the truth or parts of the truth and argued that this could be beneficial and help to protect the next of kin.

Conclusion: The results indicate various barriers for truth-telling like level of experience and will to shared decision making. Reflecting on truth-telling together in the stroke team can be valuable and contribute through inter-professional sharing of knowledge. This in its turn have the potential to lead to more well-thought decisions resting on ethically explicit grounds and thereby might promote more ethically justified care, benefiting the patient.

#### **Moral distress in undergraduate students: Advances of conceptual framework**

*Heloíza Maria Siqueira Rennó (1), Maria José Menezes Brito (2), Flávia Regina Souza Ramos (3), Carolina Caram (2), Mara Ambrosina de Oliveira Vargas (3), Beatriz Caçador (4)*

*(1) Federal University of São João del-Rei, Brazil*

*(2) Federal University of Minas Gerais, Brazil*

*(3) Federal University of Santa Catarina, Brazil*

*(4) Federal University of Viçosa, Brazil*

Health field is wide of ambiguities, which might tease in nurses' experiences involving moral problems. Moral problem can be consider as a trigger to cause moral distress. The theme moral distress in nurses has been studied and deepening by researches from different countries. Studies point out that moral distress is a process whose moral experience is considered singular, once subjects become morally responsible by action. In this way, professionals came across to moral problem, make judgment about it, but were unable to act regarding their values, characterizing moral distress. This is, moral deliberation is interrupted due obstacles which unable professional's moral-ethical positioning against a moral problem. A multicentric research has been developed by Brazilians researchers related with a construction of the scale of moral distress of Brazilian nurses. It is important theoretical advances in this topic considering some weakness of concepts and huge amount of descriptive studies. Principal aim of this project was propose elements concepts, which compose the moral distress process such as moral sensitivity, moral deliberation and stagnation in uncertainty constituting the ethical-moral subject. One of the studies part of this project aimed to analyze the developing process of ethical and moral skills and its relation to the moral distress of students during nursing education, especially during curricular internship. It was a multiple case study of qualitative approach realized in two higher public education institutions with the participation of 58 nursing undergraduate students. Together, the results show that curricular internship contribute to development of ethical-moral skills in students

due experiences of moral problems. However, these students have founded obstacles to face moral problems causing feelings such as anguish, frustration, impotence, and moral distress whose consequently cause illness, school dropout and reduced professional resistance. Thus, it is important that curricular internship must be organized making possible to student develop ethical-moral skills avoiding trigger of moral distress. The principal theoretical implication of this study was advances in conceptual framework proposed to moral distress of nurses analyzes within undergraduate students perspective. This advances are related to the inclusion of socialization process as element that compose the moral sensitivity and the process of development of ethical-moral competencies compound whole moral distress process, including moral sensitivity, moral deliberation and moral distress. This was possible due this study assume moral distress as a process which constitute the ethical-moral subject.

Funding Statement: - Coordination for the Improvement of Higher Education (CAPES/Brazil); - National Council for Scientific and Technological Development (CNPq/Brazil); - Emerging Leaders in the Americas Program (ELAP).

### **Palliative sedation for existential suffering: as systematic review of argument-based literature**

*Paulo Rodrigues (1), Jasper Crockaert (2), Chris Gastmans (3)*

- (1) Université catholique de Louvain, Institut de recherche Religions, Spiritualités, Cultures, Sociétés, Belgium
- (2) Université catholique de Louvain, Faculty of Medicine, Belgium
- (3) Katholieke Universiteit Leuven, Centre for Biomedical Ethics and Law, Belgium

Background: Palliative sedation is an intervention at the end-of-life for controlling refractory physical suffering, but it has also been used for refractory existential suffering, which prompts a controversial ethical discussion calling for a foundation in ethical arguments.

Aims: To collect, to describe, to analyse, to interpret and to discuss ethical arguments and foundational concepts appearing in argument-based literature regarding palliative sedation for refractory existential suffering (PS-ES).

Design: A systematic review of argument-based bioethics literature following the *Peer review of electronic search strategies* (PRESS) guideline and the *Preferred reporting items for systematic reviews and meta-analyses* (PRISMA) statement.

Data sources: Searches were performed in PubMed, CINAHL, EMBASE, Philosopher's index, PsycINFO, PsycArticles, Scopus, Science direct, Web of science, Pascal-Francis and Cairn. Studies included in this review met the following inclusion criteria: articles published in peer-reviewed journals till 31<sup>st</sup> of December 2016, written in English or French, with focus on ethical arguments related to palliative sedation for existential suffering.

Results: A total of 18 articles, from 1998 to 2016, were included in the review. The analysis of the selected articles revealed foundational concepts grounding the ethical debate on PS-ES, such as mind-body dualism, existential suffering, refractoriness, terminal condition and imminent death. Specific ethical principles have been used to build argumentations regarding PS-ES, such as the principle of double effect, the proportionality principle and de four principles of biomedical ethics.

Conclusion: The PS-ES debate needs to clarify its terminology and to systematise ethical arguments in a more effective way. Anthropological presuppositions, such as the dualism mind-body, underlie the debate and need to be elucidated by an interdisciplinary approach.

### **Role of nurses in the process of euthanasia in the Netherlands**

***Sabine Ruppert (1)***

*(1) University of Witten/Herdecke, Germany*

In the evolvement of the regulated euthanasia practice in the Netherlands, Nursing Care as a profession hardly played any official role due to the fact that euthanasia was seen as sole responsibility of the physicians. Nurses, however, are in practice highly involved in all phases of the euthanasia process. They have a significant position where a high degree of competence and professionalism is required.

The aim of this empirical paper is a comprehensive account of the current euthanasia practice in the Netherlands from the perspective of nurses and the description of the role of nurses in the implementation of euthanasia. Data were collected by means of semi-structured interviews with 23 Dutch nursing staff and experts. The format chosen for the interviews was based on the concept of the problem-centered interview by Witzel (1982, 1985). Interviews were done in Dutch. Data analysis was performed using an interpretive-reductive process, namely the structuring content analysis by Mayring (2003).

Patients frequently make their first euthanasia request to nurses. As a consequence patients will be asked in detail by nursing staff in order to assess the unambiguousness of their request. In particular, the voluntary nature of the patient's desire for euthanasia is scrutinized.

In the decision-making process physicians and nurses have many conversations with patients to learn the reasons for their euthanasia request and discuss treatment options. In the preparatory phase nurses have frequent and intensive discussions with the patient about euthanasia itself and her or his wishes in this respect. In the interviews, many nurses talked about the special situation of the planned death and described the very strange feeling to know the exact timing of the patient's death. Organization and preparation of euthanatica is a medical activity according to the law, as well as the application of a venous access and the administration of euthanatica. In some cases nurses take over these activities - often because of their skills. Nurses describe the moment of euthanasia as an emotionally very touching situation. After performing euthanasia taking care of the corps and of the patient's family are important tasks of nurses. Another relevant aspect is the personal reflection of the event either alone or within a team. Frequently nurses have created rituals to cope with their emotions after euthanasia.

The results of this study clearly show that the process of executing euthanasia in the Netherlands is still an exceptional situation despite the now ten-year-old practice and leaves a deep impression upon everyone involved. The nurses act as information mediators, supporters, advocates and supervise the process. In order to fulfill these different roles nurses require sophisticated professional, ethical and personal skills. Likewise, organizational ethical issues are a prerequisite for good nursing care and support of people asking and receiving euthanasia. Since the legal legitimacy for some of the nurses'

activities is lacking, legislative amendments would be highly desirable in order to make the most comprehensive and responsible role of nursing in the process of euthanasia legally and socially visible. Finally, the nursing profession has to reflect their principles, values and standards related to euthanasia.

#### References

- Mayring, P. (2003). *Qualitative Inhaltsanalyse. Grundlagen und Techniken*. Weinheim: Beltz.
- Witzel, A. (1985). Ethnographic research in education. In: R.M. Jaeger (Ed.), *Complementary methods for research in education* (187-210). Washington: AERA.
- Witzel, A. (1982). Das problemzentrierte Interview. In: G. Jüttemann (Hg.), *Qualitative Forschung in der Psychologie* (227-256). Weinheim: Beltz.

### **Difficulties of Nurses Involved with Families Making Proxy Decisions on AHN at Elderly Care Facilities**

*Kyoko Saeki* (1)(2), *Sayuri Suwa* (2)

(1) *School of Nursing, Faculty of Health Care Sciences, Chiba Prefectural University of Health Sciences, Japan*

(2) *Graduate School of Nursing, Chiba University, Japan*

Introducing artificial hydration and nutrition (hereinafter called AHN) is a treatment option for the elderly having difficulties in oral intake. However, there are limitations in providing medical services at elderly care facilities. Furthermore, if an old person has difficulties eating orally, it has often been observed that their condition makes them unable to express their intentions, in which case, their family is forced to make decisions on matters of life and death. Even after a decision has been made, the family is still conflicted about whether or not their decision was appropriate. Therefore, a nurse is expected to help such old persons and their families.

Thus, this study aimed to elucidate the difficulties of nurses involved with families making proxy decisions regarding AHN. For the study design, we used a qualitative, descriptive design. We conducted semi-structured interviews with four nurses who had experience in managing elderly persons who were in a condition requiring assessment for a possible introduction of AHN, as well as their families. The subjects were all female nurses who had experience working at care facilities for 1 to 12 years.

As a result of our analysis, the following five categories were extracted: “responding to families who are unable to make a decision even after many times of explanation,” “family’s desire to continue the old person’s oral intake despite a high risk of accidental swallowing,” “judgment of being in a terminal stage,” “indecisiveness of the families,” and “inconsistent judgments of doctors.”

As an old person, even if they are unable to eat at a given point of time, they may eat after a while, or if the hydration is relieved by intravenous drip infusion, it makes difficult to make a “Judgment of being at a terminal stage.” The nurses were able to understand the “indecisiveness of the family” about whether or not AHN should be provided; however, they found it hard to make up their minds regarding when the final confirmation of the family’s intention had to be made. Further, they had difficulty in judging whether the patient was at a terminal stage or not.

Regarding the families—from whom the nurses realized their indecisiveness despite repeated explanations—the situations wherein “the family desires intravenous drip infusion, but the facility is not in a position to do so, yet the family does not want to make the patient leave the care facility they are accustomed to,” and “the family finally decided to shift the old person to a hospital, since they are unable to eat at all,” were verbally explained. From these, it is suggested that the families are able to make a decision, but unable to accept that the old person is at a terminal stage.

Based on these findings, if a situation arises wherein the introduction of AHN is discussed, it is considered necessary to support the family to make a proxy decision not only regarding the choice of treatment but also to accept the fact that the old person is at the terminal stage.

### **The dialectical movement between deprivation and preservation of a person’s life space: A question of nursing home residents` dignity**

*Berit Sæteren (1), Anne Kari Tolo Heggstad (1), Bente Høy (2), Britt Lillestø (3), Åshild Slettebø (4), Vibeke Lohne (1), Maj-Britt Råholm (5), Synnøve Caspari (1), Arne Rehnsfeldt (6), Lillemor Lindwall (1)(7), Trygve Aasgaard (1), Dagfinn Nåden (1)*

*(1) Oslo and Akershus University College of Applied Sciences, Oslo, Norway*

*(2) VIA University College, Århus, Denmark*

*(3) Nord University, Bodø, Norway*

*(4) University of Agder, Grimstad, Norway*

*(5) Sogn and Fjordane University College, Førde, Norway*

*(6) Stord/Haugesund University College, Stord, Norway*

*(7) Karlstad University, Karlstad, Sweden*

Dependency and needs in different areas of life make elderly people particularly exposed and vulnerable to dignity deprivation and suffering. When moving into a nursing home, elderly people frequently go through many life-changing events, which may cause suffering. Maintaining personal life space in relation to the physical environment, confirming interpersonal relations and a feeling of inner freedom and worth is part of experiencing dignity, despite the onset of aging, disease and disability. The need for privacy varies from individual to individual, but living in nursing homes in most cases will lead to decreased personal life space. The decrease affects not only physical space but also a person’s freedom and autonomy. This study emphasizes the importance of promoting personal life space in nursing homes in order to protect the residents’ responsibility and inner freedom and thereby their dignity,

The purpose of this cross-country Nordic study is to acquire a deeper understanding of what older nursing home residents do themselves in order to maintain their dignity.

The study has a hermeneutic design inspired of Gadamer’s philosophical hermeneutic. Twenty-eight residents, eight men and twenty women aged 62 – 103 years from six different nursing homes in Scandinavia were interviewed.

Many of the residents are able to utilize their inner health resources such as self-respect, inner strength, willpower, remembrances and living in the presence to protect themselves and their personal life space in spite of hindrances, where other residents give up and resign.

The results showed that the residents tried to expand their life space, both physical and ontological in order to expand their life space, so as to be responsible for their own lives, to experience freedom and being at home. Main themes identified were striving for being at home, striving for inner freedom and autonomy, and striving for a meaningful life.

Giving more attention to the residents' need for spaciousness in nursing homes physically, relationally and ontologically, and actively stimulate the residents' inner health resources, will contribute towards maintaining and promoting dignity, stimulating health and alleviating suffering in old age.

### **The process of re-harmonising connectedness as an ethical challenging experience**

*Tiziana ML Sala Defilippis (1), Ann Gallagher (1), Katherine Curtis (2)*

*(1) University of Surrey, UK*

*(2) Department Nursing and Clinical Sciences, Bournemouth University, UK*

BACKGROUND: Nursing is a moral practice that aims at the good of patients, families and communities (Gastmans, Dierckx de Casterlé and Schotsmans, 1998). However, applying ethical principles in practice is not a problem-free enterprise (Lützné *et al.*, 2003; Schluter *et al.*, 2008; Epstein and Hamric, 2009; Epstein and Delgado, 2010) due to the particular position nurses have within the health care system, institutions and the care teams. Nevertheless the majority of nurses continue to work ethically despite moral tensions and moral distress. One possibility is that the events that follow a morally distressing situation constitute a process of moral resilience.

OBJECTIVES: This study aimed to examine the main concerns among intensive care nurses in respect of ethical practice; to investigate how nurses continue to practice in an ethical way despite pressures, tensions and conflicts.

DESIGN: This is a qualitative study drawing on Glaser and Strauss' (1967) version of grounded theory.

The study involved 16 nurses working in intensive care.

FINDINGS AND THEIR IMPLICATION FOR PRACTICE: Moral resilience among nurses develops from harmonising connectedness within the social interactions in which nurses are involved.

When nurses achieve in harmonising connectedness they are able to experience moral wellbeing. The state of moral wellbeing described by nurses in this study is a state of grace, where nurses feel well and are well and when they are put in the condition of doing well according to their inner moral ideal.

Nevertheless, nurses' moral life is continuously challenged and their connectedness is under threat due to their intense involvement in social interactions with others in the ethically loaded environment in which they work. Moral coping strategies and their outcomes are discussed within the context of the findings of this research. Coping strategies addressing disharmonious connectedness can have mainly two outcomes, they are: consolation and establishment of a new harmonised connectedness and resignation and alignment with reality. These two strategies will be illustrated and explained in depth.

## REFERENCES

- Epstein, E. G. & Delgado, S. 2010. Understanding and Addressing Moral Distress. *The Online Journal of Issues in Nursing*, 15(3).
- Epstein, E. G. & Hamric, A. B. 2009. Moral distress, moral residue, and the crescendo effect. *Journal of Clinical Ethics*, 20(4), 330-342.
- Gastmans, C., Dierckx de Casterlé, B. & Schotsmans, P. 1998. Nursing considered as moral practice: a philosophical-ethical interpretation of nursing. *Kennedy Institute of Ethics Journal*, 8(1), 43-69.
- Glaser, B. G. 1978. *Theoretical sensitivity*. Mill Valley: Sociology Press.
- Glaser, B. G. 2005. *The grounded theory perspective III: theoretical coding*. Mill Valley: Sociology Press.
- Glaser, B. G. 2011. *Getting out of the data*. Mill Valley: Sociology Press.
- Glaser, B. G. & Strauss, A. L. 1967. *The discovery of grounded theory : strategies for qualitative research*. New York: Aldine Publishing Company.
- Lütznén, K., Cronqvist, A., Magnusson, A. & Andersson, L. 2003. Moral stress: synthesis of a concept. *Nursing Ethics*, 10(3), 312-322.
- Schluter, J., Winch, S., Holzhauser, K. & Henderson, A. 2008. Nurses' Moral Sensitivity and Hospital Ethical Climate: a Literature Review. *Nursing Ethics*, 15(3), 304-321.

**Family caregivers' experiences of End of life decision making in demented patients**

Neda Sanaie (1), Mahboobe Shali (2), Fatemeh Bahramnezhad (2), Habibe Shahbazi (3), Bahareh Shahbazi (4)

(1) Shahid Beheshti University of Medical Sciences, Tehran, Iran

(2) Tehran University of Medical Sciences, Tehran, Iran

(3) Moheb\_e\_Mehr Hospital, Tehran, Iran

(4) Imam khomeini Hospital, Tehran, Iran

**Introduction:** Population ageing and the existing burden of care for family caregivers indicate that there will be enormous pressure on families in the future to provide adequate and culturally appropriate care. Most demented patients are cared for at home by family members. Family members play an important role in the selection of patients' doctors, hospitals, treatment options, and provisions of care. Family caregivers of elderly relatives with dementia are increasingly faced with decisions about appropriate treatment for medical complications in the late stages of these diseases.

**Aim:** This study is among the first to describe family caregivers' role as decision makers and their experience with regards to the decision-making process at the end of life of a loved one with dementia.

**Method:** Tape-recorded open-ended unstructured interviews were conducted. The research sample consisted of 30 family caregivers involved in the care decisions for an elderly relative with dementia, as diagnosed medically. The texts were analysed using a phenomenologic hermeneutic approach.

**Results:** The essence of the family caregivers experience themes during the decision-making process included: understanding the treatment process step by step, role pressure, constructing care-taking ability, endeavouring to maintain family functioning while preparing for care and deliberate consideration to make the correct decision.



Conclusion: The results of this study provide evidence-based essential knowledge that will assist the management of such decision-making processes. There is a need to develop a better understanding of the experience of people with dementia at the critical point of diagnosis disclosure in order to design supportive interventions. It can help nurses' efforts to integrate families into decision-making processes in clinical settings to facilitate family communications and improve patients' and caregivers' satisfaction with treatment decisions. The findings provide valuable information for healthcare providers helping patients and their caregivers make treatment decisions through a shared, informed, decision-making process.

### **Nurses and the Nazi T4 Program: Focusing on mentality of complicities**

Aiko Sawada (1)

(1) Fukuoka, Japan

During the Nazi Era, a huge number of innocent people were killed because they were deemed “unworthy of living”. In the crimes committed by the Nazis, doctors worked as a major force in the killing system. In fact, doctors who had good understandings of Hitler’s intention were key players in the T4 program that aimed to eliminate the mentally handicapped people.

While many studies on the Nazi crimes and doctors’ involvement have been published, hardly any attention has been paid to nurses who worked with and assisted the doctors. It is true that doctors worked as a major force of the T4 program. However, they could not have accomplished their roles without nurses’ assistance. Therefore, nurses’ involvement should be also studied. In this presentation, I will focus my attention on nurses’ involvement in the Nazi crimes.

Being accused of Nazi crimes after the war, the Nazi doctors defended themselves by claiming that they reluctantly participated due to orders from above. And the nurses also claimed that they had had no other choice than obeying doctors’ order. Despite their claims, it seemed to be a rare case that their disobedience put their lives at risk in the T4 program. On the contrary, they voluntarily used tactful techniques to fulfill their roles.

In my presentation, first of all, I will analyze the nurses’ actions as accomplices through the existing documents on the T4 program. Killing methods used in the T4 program were (1) gas (2) poison and (or) starvation (3) shooting. I will examine how nurses were involved in the killing process by these methods.

Then, I will examine the mentality which makes the nurses participate in these crimes. I will try to analyze their mentality along with the following points: (1) logic of moral justification for the nurses’ actions (2) structure of “Doubling” underlying their mentality (3) “Psychic Numbing” with actions.

Finally, I will stress the importance of looking at the dark era of nursing history in nursing education as a conclusion.

**Working as a nurse: Moral distress and job features**

*Rafaela Schaefer (1)(2), Elma Zoboli (2), Margarida Vieira (1)*

*(1) Catholic University of Portugal, Porto, Portugal*

*(2) São Paulo University, Brazil*

Background: Moral distress was for the first time presented by Andrew Jameton, in 1984, describing a kind of suffering that nurses may experience when they cannot act according to a previous moral decision. This kind of situation may lead to a perceived wrongdoing, either by action or by omission, resulting mainly in negative consequences, as frustration, powerlessness, anger, sleep disorders and fatigue.

Objective: To present the Moral Distress Risk Scale and the results of its application in southern Brazil. Research design: a cross-sectional study was realized with a convenience sample of 268 nurses from hospitals and primary health care services. Data were collected between March and June 2016 and submitted to exploratory factorial analysis, to psychometrically test the scale, and to t Student and ANOVA tests, to identify significant differences between the variables. Tests were performed with SPSS 22.0.

Ethical considerations: This research has ethics committee approval.

Findings: The scale is composed by 30 items, organized in 7 factors: organizational and management issues, end of life care, autonomy, workload, security, resources and conflicts. Acceptable reliability is evidenced through Cronbach's Alpha (0.913), total variance explained (59%), KMO (0.896) and a significant Bartlett (<0.001). Most research subjects were women (89.2%), mean age of 36 years (SD ±8.6) and a 10-year nursing experience (SD ± 8.1). About 63.8% of nurses were working at hospital care services, while 36.2% were from primary health care services. At least 15.4% were working more than 40h per week and 60.4% were doing overtime work. Most of the participants had already experienced moral distress before (73.6%). In addition, 36.9% demonstrated willingness to live their job position. Moral distress appears to be significantly higher between those nurses working in hospitals (.000), more than 40h per week (.002) and who usually do overtime work (.003). Nurses who had experienced moral distress before seems to be more susceptible to experience it again (0.005), which also happens with those nurses thinking about to leave their job position (.000). Moral distress seems not to be related with gender or age.

Discussion: Nurses are working in very complex socio-political healthcare contexts, where the probability of experiencing moral distress is high. The use of reliable tools to help in identifying and dealing with moral distress may increase the probability of success of the interventions.

Conclusion: Psychometrics results reveal that the scale is able to identify risk for moral distress in nurses working in hospital and primary health care services. The use of this kind of tool may help professionals to express their concerns, preventing that moral distress become part of the working routine.

## **Losing the integrity: An ethical dilemma in palliative phase in nursing homes**

*Ramona Schenell* (1), *Anneli Ozanne* (1), *Susann Strang* (1), *Ingela Heno* (1)

(1) *Sahlgrenska academy, Institute of Health and Care Sciences, University of Gothenburg, Gothenburg, Sweden*

**Background:** Residents in palliative phase in nursing homes are dependent on others for their daily living. To promote self-determination staff has to support the residents in both decision making and execution of decisions made.

**Aim:** The aim was to describe staffs' experiences of ethical dilemmas regarding self-determination in palliative phase in nursing homes.

**Method:** Interviews with 20 nurses, enrolled nurses and physicians working in nursing homes were analyzed using inductive content analyses. One theme and three sub themes were found.

**Results:** The theme *Losing the integrity* illuminates how staff experienced lack of resources, lack of care planning and lack of insight as obstacles for the residents' self-determination. The integrity of the residents was violated when the staff had to transgress the self-determination due to shortcomings in the organization, way of working and cognitive impairment among the residents. Acting against the residents' wishes caused feelings of being inadequate and abusive and were described as unworthy and unethical.

*Experiencing lack of resources* illuminates how the staff balanced between doing good for the residents individually and doing good for the ward in large. Lacking resources had consequences for the residents in unfulfilled wishes, reduced flexibility, long waiting time, and risk of being left alone when dying. Being forced to prioritize when resources did not cover the needs was described as an ethical dilemma by the staff.

*Experiencing lack of care planning*, including lack of discussions about end of life care together with the residents illuminates how staff felt that this lack could lead to unwanted actions and prolonged suffering. When the residents' health impaired, relatives had difficulty of letting go and could request intravenous fluids, antibiotics, hospital stays, tube feeding and cardiopulmonary resuscitation (CPR). If "No CPR" was not documented in the medical record, CPR had to be performed when sudden cardiac arrest appeared. This was described as an ethical dilemma as the staffs' common understanding was that residents in palliative phase opposed life prolonging actions as it increases their suffering.

*Experiencing lack of insight* illuminates how staff felt that the self-determination among residents deteriorated due to e.g. cognitive impairment or dementia. Staff described ethical dilemmas when they felt obligated to take actions against the residents' will to protect them from their own decisions. In some cases the staff justified violations of the residents' self-determination, but in other cases they felt like committing abuse. Even though staff was acting for the good of the residents, they felt bad to offend their self-determination.

**Conclusion:** The complexity of ethical dilemmas in relation to self-determination in nursing homes concerns insufficient resources, inadequate care planning, and impaired cognitive abilities. As self-determination is seen as the goal by the staff, dilemmas arise when staff cannot fulfill wishes or are

forced to take actions against the residents will. To reduce these dilemmas, it might be relevant to involve the entire organization in promoting self-determination for the residents.

**Ethical issues in long term care facilities for the elderly from nurses' perspective: First qualitative data from Austria**

*Karoline Schermann (1), Magdalena Flatscher-Thöni (2), Nina Lorenzoni (2), Daniela Deufert (1)*

*(1) Department of Nursing Science and Gerontology, UMIT – Private University for Health Sciences, Medical Informatics and Technology, Austria*

*(2) Department of Public Health, Health Services Research and HTA, UMIT – Private University for Health Sciences, Medical Informatics and Technology, Austria*

Background: In long term care facilities, nurses are part of different relationships concerning residents, relatives and colleagues, imbedded in the organizational and legal structures of the facilities. This can cause possible areas of conflicts, including ethical challenges. In their daily routine, nurses are confronted with conflicting situations and have to decide on ethical issues. Therefore, nurses have to consider the ethical core concepts of non-maleficence, autonomy, justice and beneficence (Beauchamp, Childress, 1994). In other words, nurses are responsible for the ethical quality of nursing care (Teeri et al., 2006). Compared to hospitals, ethic counsels or ethic committees are rarely implemented in long term care facilities in Austria. Consequently, nurses have nearly no support on ethical decision making in their daily routine, especially when talking about systematized ethical consultations.

Aim: The aim of the study at hand is to create a better understanding on ethical issues from the nurses' point of view in long term care facilities focusing on daily nursing practice in Austria.

Method: The study is part of a larger research project focusing on ethical and legal issues in long term care facilities. A qualitative research approach is applied to create a better understanding for the ethical issues in long term care facilities. Between May and August 2016, 28 interviews were conducted in Austria. The interviewees were nurses, nursing assistants, head nurses and directors of the participating long term care facilities. The interviews were recorded and transcribed afterwards. For the analysis of the interviews the PC-supported method GABEK® was used.

Results: The first analyses of the data show that nurses are confronted with two major ethical issues in their daily routine - first, relationships to residents and their relatives, second organizational issues. The interviewees focused on the challenge nurses face in the interaction with residents' relatives in different situations (e.g. dying residents) due to the shortened remaining time. Furthermore, nursing assistants have to decide in situations for residents they are not trained for (e.g. pharmacological decisions) since there are not enough nurses available in the facility. Therefore, insecurity occurs in nurses and nursing assistants; especially if they have to decide whether or not to contact a physician and how to proceed with residents with a declining health status.

Conclusion: The first data demonstrate that nurses take on responsibility for ethical decisions on their own. Challenges include the focus on individual residents' needs and to consider privacy, autonomy and voluntariness of the elderly. In a long term care facility, residents and nursing staff are often confronted with intricate relationships, which potentially occur as an ethical issue. Creating knowledge

about these ethical issues is necessary to develop possibilities for ethical education and reflection for nurses working in long term care facilities. Structured ethical consultations should strengthen nurses on ethical decision making in their daily routine.

### **Walking with patients: What can we learn from everyday encounters between patients and first year nursing students?**

Sam Schrevel (1), Meralda Slager (1)

*(1) The Hague University of Applied Sciences, The Hague, The Netherlands*

Faced with a changing demographic composition of society and a changing burden of disease, the Dutch government focuses on health reforms that stresses the empowerment and self-sufficiency of patients. This change of focus from 'curative care' to 'disease management' demands health education to change accordingly. In the newly developed curriculum of the Nursing bachelor's degree at the Hague University of Applied Sciences (THUAS) the crucial element patient participation. We hold the believe that the experiences and knowledge of patients are essential to train health professionals who are equipped work in health care the coming decades.

To realize this, the students will learn about patient participation theory, methods and techniques. Most importantly, they will participate in programs where they learn directly from the experiences of patients. In collaboration with a volunteer organization, the students are coupled with an individual who is need of additional care. For example, students are coupled with lonely elderly people, chronically ill patients or children from families with health problems. Last year, 110 students are linked to around 50 people with a variety of health or social problems.

In this lecture we will present the outcome of an evaluation study of the first year of this buddy project. Four focus groups will be held with students who participated in the program. Additionally, interviews will be conducted with the teachers involved in the program and with the people who received students from THUAS. We will discuss the experiences from the perspectives of these participants and evaluate: 1) to what extent the experiences of the students have an added value for their learning; 2) to what extent teachers are able to embed the experiences of students in their courses and 3) what the perspectives are of patients who received a student from THUAS.

Volunteer organizations are in desperate need for volunteers, but the question arises whether unexperienced students well enough equipped to support these people. In this presentation we will focus specifically on the ethical questions that arise from this project.

### **The role of an ethics committee in a nursing home: Not my cup of tea?**

Ursula Segaert (1)

*(1) Woonzorgnet Dijleland, Leuven, Belgium*

Background: The residential care network Dijleland (Belgium) encompasses four residential care centres where about 350 residents receive care. Although not legally required, both from the management and the work floor, the need for ethical reflection and support resulted more than 10

years ago in the creation of an ethics committee. In this presentation we will present activities and principles that contribute to a successful and fruitful functioning of an ethics committee in a nursing home.

Composition and principles: The ethics committee is composed of members that have a diverse background: members from the 4 houses (being nurse, doctor, policy collaborator, manager, etc.) that both have work floor and policy experience, as well as a few external experts. We meet only 4 times per year, but make good progress thanks to working groups that prepare specific aspects in between these meetings. Ethics education of the members is stimulated.

Activities and instruments: The ethics committee is involved in several activities: developing ethics opinions, elaboration care pathways, ad hoc advice for cases, stimulating ethics training etc.

Examples topics that were object of ethics opinions are: overuse of medication, our residents in the media, an in-house mortuary, end of life planning, euthanasia, etc. We will elaborate the ethics opinion on euthanasia: genesis, different steps, flowchart, implementation on the floor, communication with residents/families and employees, debriefing, and monitoring.

Training and lessons learned: Essential materials that contribute to the success of our functioning are: (1) bottom-up approach; (2) not only focusing on the big ethical questions (e.g. Euthanasia) but also on the daily care ethics; (3) support from management and work floor; (4) good communication with all stakeholders; (5) balanced composition of ethics committee; (6) ethics training of employees. We will actively illustrate this training aspect with the example of the 'dilemma game'.

***"Family caregivers don't have a lobby. And care-recipients neither": Subjective views on dependency and the provision of care of three involved parties in home nursing.***

*Anna-Henrikje Seidlein (1), Ines Buchholz (2), Maresa Buchholz (2), Sabine Salloch (1)*

*(1) University Medicine Greifswald, Institute for Ethics and History of Medicine, Germany*

*(2) University Medicine Greifswald, Institute for Community Medicine, Germany*

Background: Conceptions of health, illness and care dependency have been widely discussed in theoretical debates. Parallel to these, numerous empirical studies have focused on subjective perspectives in relation to specific diseases and have shown their significance, for example with respect to therapeutic adherence. There is a growing number of patients in need of long-term care and the proportion of those receiving it by informal caregivers (IC) and professional caregivers (PC) at home has increased. However, only few studies so far have investigated the personal meanings of complex multimorbidity requiring long-term home nursing.

Methods: Data was obtained by conducting semi-structured qualitative interviews with eight informal caregivers, ten professional caregivers and ten care-recipients in long-term home nursing arrangements in the Northeastern part of Germany. The participants were asked about their daily life experiences of receiving care at home, the impact of dependency and their subjective understanding of health and illness. Furthermore, the interviews intended to capture the participants' perceptions of the appropriateness of care. All interviews were audiotaped, transcribed verbatim and qualitative content analysis according to Mayring was performed using MAXQDA 12 software.

Results: Health was understood as a mental and emotional well-being, for which social relationships (e.g. family ties) play an outstanding role. It was described as a capability that enables the participants to live their own lives, whereas illness was linked to symptoms of the body and the loss of self-fulfillment. The evaluation of the nursing care provided varied in the views of the different stakeholder groups and with respect to various aspects of daily life. Underprovision of care, as experienced by care-recipients, was particularly described as a mismatch between the desired social inclusion, communication and mobility and the self-perceived current situation. PCs were aware of those needs and reported on extra efforts to meet their clients' wishes. ICs perceived most of the problems concerning underprovision of care as being related to a missing delivery of personal aid and care equipment where they have to overcome immense bureaucratic obstacles to receive what they need. Moreover home nursing was described as being ambivalent: For example professional care enables social participation but, at the same time, makes it more complicated as not only the care-recipients' lives but also the ICs' social activities and privacy are influenced by professional home nursing.

Conclusions: The desire for social participation was a major theme of all participants. It is a prerequisite for subjective well-being despite suffering from multiple chronic conditions. The impact of home nursing arrangements on the social and economic situation of informal caregivers has to be taken into consideration to meet not only the care-recipients' but also the informal caregivers' needs and to prevent negative consequences of home care. Besides, the study demonstrates that long-term care insurance does not cover all aspects of care perceived as relevant for subjective quality of life by care-recipients. Hence, there is an additional need for innovative concepts meeting the challenge of comprehensive care, particularly in economically weak regions with a low population density.

#### **Quality dementia care: Prerequisites and relational ethics among multicultural healthcare providers.**

*Gerd Sylvi Sellevoid (1), Veslemøy Egede-Nissen (2), Rita Jakobsen (1), Venke Sørli (1)*

*(1) Lovisenberg Diaconal University College, Norway*

*(2) Oslo and Akershus University College, Norway*

Background: Many nursing homes appear as multicultural workplaces where the majority of healthcare providers have an ethnic minority background. This environment creates challenges linked to communication, interaction and cultural differences. Further, the healthcare providers have varied experiences and understanding of what quality care of patients with dementia involves.

Purpose: The aim of this study is to illuminate multi-ethnic healthcare providers' lived experiences of their own working relationship, and its impact on quality care for people with dementia.

Research design: The study is part of a greater participatory action research (PAR) project: "Hospice values in the care for persons with dementia". The data material consists of extensive notes from seminars, project meetings and dialogue-based teaching. The text material was subjected to phenomenological-hermeneutical interpretation.

Participants and research context: Participants in the project were healthcare providers working in a nursing home unit. The participants, came from 15 different countries, had different formal qualifications, varied backgrounds and ethnic origins.

Ethical considerations: The study is approved by the Norwegian Regional Ethics Committee (REK) and the Norwegian Social Science Data Services (NSD).

Findings: The results show that good working relationships, characterized by understanding each other's vulnerability and willingness to learn from each other through shared experiences are prerequisites for quality care. The healthcare providers further described ethical challenges as uncertainty and different understandings.

Discussion: The results are discussed in the light of Lögstrup's relational philosophy of ethics and the concepts of vulnerability, ethic responsibility, trust and openness of speech.

Conclusion: The prerequisite for quality care for persons with dementia in a multicultural working environment is to create arenas for open discussions between the healthcare providers. Leadership is of great importance.

### **Assessing the quality of informed consent in surgical patient: A cross-sectional study**

*Mahboobe shali (1), Fateme Bakhshi (1), Mansoreh Sepehri nia (2), Atefe Vaezi (2)*

*(1) Tehran University of Medical Sciences, Tehran, Iran*

*(2) Zanzan University of medical Sciences, Zanzan, Iran*

Introduction: The doctrine of informed consent serves the ethical goal of respecting patients' rights of self-determination. All medical codes of ethics now hold that Health provider system have a duty to obtain the consent of patients before undertaking procedures. If consent has not been given for a particular procedure the patient can claim to have been assaulted.

Aim: We aimed to Assessing the quality of several aspects of the informed consent process for surgery.

Method: We did a cross-sectional study to which we recruited 500 adults who had surgery in surgical service of a university teaching hospitals in Zanzan, Iran. Participants completed a voluntary multiple-choice questionnaire on the informed consent process. All patients consented to take part in this study after verbal and written explanations. ANOVA and correlation coefficients were used to test the relationships between variables.

Results: A total of 500 patients were participated. The population had a mean age ( $\pm$ SD) of  $43.3 \pm 8.4$  years (range 18-75); 62% were Male. 56% of patients stated that they had a poor understanding of the risks and complications of the procedure. Only 33 patients (6.6%) reported being informed in detail, and 289 (57.8%) reported that they received only basic information.

Conclusion: Understanding the values and health goals of the patient is to know the patient as a person and is essential for surgeons to provide appropriate and respectful care. To Information must be provided about what is to be done and why, and what the foreseeable risks and consequences of treatment are. Competent patients understand, remember and use the information provided to them to either consent to, or refuse, treatment. Further attention should be drawn on enhancing patients' understanding regarding several components of the informed consent process for surgery.



### **Nurses and caregivers' perspectives at the end of life care: A phenomenological study**

*Mahboobe shali (1), Soodabe Joolae (2)*

*(1) Tehran University of Medical Sciences, Tehran, Iran*

*(2) Nursing Care Research Center, Iran University of Medical Sciences. Iranian Academy of Medical Sciences, Tehran, Iran*

**Introduction:** Providing appropriate end of life care has become a primary concern of nurses and the public. FARS palliative care center in Iran supports main client groups including patients with a diagnosis of cancer, and those with other chronic illnesses. From the evidence to date, family of patients dying from cancer experience a considerable needs in terms of symptom control and psychosocial support and there is a limited information on nurses and other caregivers' views about end of life care in Iran.

**Aim:** This paper reports a study exploring the nurses and caregivers' experience of end of life care in FARS palliative care center in Iran.

**Method:** A phenomenological study was carried out. A purposeful sample of 30 nurses and 30 caregiver of dying patients were interviewed in 2016-2017. Colaizzi's seven stage approach was used for data analysis.

**Results:** The major categories emerged from the caregivers and nurses experiences were: building trust, being part of the family; refilling with fuel along the journey of living and dying. The nurses showed high levels of commitment, and imputed a sense of meaning and purpose to their work.

**Conclusion:** It is important to learn from patients and their caregivers needs, where appropriate family-centred support may be most effective. Trust, the achievement of the goals of caregivers and nurses, caring and reciprocity are important elements of nurse-caregivers relationships in end-of-life care. The results indicate that nurses need the resources such as time, improved methods of communication and cooperation as well as more support in order to give quality palliative care and achieve satisfaction with the outcome. We suggest that a more coherent approach to research and education is required, in particular strategies that explore how caregivers and nurses can work together in exploring experiences of illness in order to develop more proactive approaches to end of life care.

### **Repairing damaged identities: Compassion and the hidden curriculum in nursing education**

*Anne Simmonds (1)*

*(1) Faculty of Nursing, University of Toronto, Canada*

Compassion has long been considered to be a taken-for granted moral imperative within the nursing profession and is reinforced to nursing students in academic settings through careful attention to standards of practice and ethical codes. Currently there are rising global concerns related to declining levels of compassion in health care, as well as reports from nursing students that their perceptions of nurses as kind and compassionate are becoming increasingly tenuous. This suggests a disjuncture between the formal, more explicit curriculum and the 'hidden' curriculum, in which students learn

values and are socialized in ways that may be unintended. The importance of examining compassionate practices in nursing education is underscored by rising rates of anxiety and stress amongst nursing students internationally, and the imperative to prepare resilient nurses who can function in increasingly complex and demanding care environments. The focus of much of the inquiry in this area to date has been on the 'gap' between care and compassion in theoretical and practice-based learning. Less attention has been paid to the moral dimensions of academic environments and the extent to which current teaching practices –specifically the relationships between students and teachers - reflect the compassionate values we claim to impart. While the context of nursing education varies widely throughout the world, the hidden or informal curriculum is grounded in interpersonal interactions occurring in any setting. It is within these settings and learning environments that values such as compassion are learned and professional identities are shaped. In this session we will explore the limits and possibilities for embedding classroom teaching practices and relationships in a pedagogy of care and compassion.

**The life of the elderly in residential care facilities: A study of autonomy and life situation of elderly people in the context of the political organisation of the facilities**

Ulla Skjødt (1)

(1) *University College Zealand, Roskilde, Denmark*

**Aim:** To examine how the political organisation of the residential care facilities in Denmark can be perceived in the practices of these facilities, and examination of which consequences this organisation has for the autonomy and life situation of the elderly.

**Methods:** The dissertation is based on a practical-philosophical approach in which theory and practice are inextricably linked as well as mutually informing each other. Thus, the autonomy of the elderly in the structural context of the residential care facilities cannot be captured and unfolded with philosophical perspectives of the concept of autonomy alone. Neither is the autonomy of the elderly drifting around in the daily practises in the residential care facilities. The autonomy of the elderly can be determined in relation to lived lives of the elderly people in their encounter with the political framework of the residential care facilities, and is therefore anthropological present in the form of practical concept(s). Empirical material is therefore generated by participant observation on wards and by interviewing elderly, relatives and employees in residential care facilities, as well as policy documents, concerning the arrangement of public help to elderly people in need of long-term care, are analysed.

**Results:** Analysis of the empirical material shows internal conditions connected to the impaired elderly who are no longer capable of leading an independent life. These internal conditions consist of physical disability, mentally problems and/or reduced cognitive ability. To meet these internal conditions of the individual impaired elderly the empirical material shows external conditions concerning the political organisation of the residential care facilities. These external conditions consist of organising residential care facilities as homes, helping performed as tasks, and using families as a resource. It turns out, that these external conditions comprise particular circumstances which acknowledge the autonomy of the elderly in a special way. This extraction of the empirical material therefore requires a closer examination of the content of the current politically dominated concept regarding autonomy of the

elderly. Analysis of policy documents shows, that the content of this concept concerns the vigour of the elderly, which is interpreted to mean taking responsibility for yourself, caring for yourself, and retaining the ability to make rational decisions.

In its generalised form this current politically dominated concept of autonomy is a standardised concept of autonomy, and it turns out to be contradictory to the life situation of impaired individual elderly people living in residential care facilities. The analysis shows, that the impaired elderly, who is not able to match up to the standardised concept of autonomy and with the correct actions embedded in it, are ignored or rendered invisible in the public market bureaucratic organisation with inherent legalised consumerism.

The consequences of the present organisational controlling ideology become particularly clear in the empirical data material, when some members of the staff fail to provide the political standardised help, and dare to make situated judgements. This means, that they meet the impaired elderly with a situated and open concept of autonomy that determines whether elderly people are perceived as individuals. Dignity in care and daily living of the impaired elderly is in these situations rendered visible.

### **Implications for educational practice - overriding the choices of mental health service users: A study examining the acute mental health nurses' perspective**

*Grahame Smith (1), Rose Khatri (1)*

*(1) Liverpool John Moores University, UK*

This study explores from a mental health nurse's perspective the experience of ethical reasoning while overriding the choices of mental health service users within an acute mental health context. When working with service users in acute mental distress a mental health nurse's clinical decisions will have a controlling element, which can lead to the service user's freedoms being restricted. This power to restrict freedoms also known as coercion can be explicit; follows the rule of law, and implicit; ways of controlling that are 'hidden'. The ethical use of this power requires the nurse to be an effective ethical reasoner and one who understands both the explicit and implicit nature of this power. Coercive power which is explicit has been thoroughly explored; however, there is limited work exploring the use of this power as an ethical and 'real-time' practice issue. In addition, there is little work exploring implicit power as an ethical issue in action.

To examine this knowledge gap this study adopts a research approach which focuses on engendering an understanding of the mental health nurse's personal meaning and experience of using both explicit and implicit coercive power. To stimulate reflexive understanding this study adopts an interpretative phenomenological analysis (IPA) approach to tease out the personal 'ethical' meaning of the participants' experiences. IPA is an idiographic mode of inquiry where sample purposiveness and analytical depth is more important than sample size. On this basis six qualified mental health nurses who had used coercive strategies while nursing service users in acute mental distress were recruited.

The semi-structured interviews were thematically and interpretively analysed using a double hermeneutic, the five superordinate themes that emerged related to the nurse as a practitioner, their values, their practice, their use of coercion, and their ethics.

In addition, the results of the study highlighted that coercive strategies are a key part of a mental health nurse's daily practice both explicitly and implicitly.

These strategies can be beneficent; however, this is dependent on the ethical reasoning ability of the nurse and the professional support they receive in practice. Being an effective ethical reasoning requires the nurse to acquire 'good habits', which is the basis for enabling the nurse work to through an ethical challenge in 'quick time', however to enhance these good habits they also need to have an 'ethical imagination'. This study recommends the education development of mental health nurses recognises that mental health nurses when using coercive power will need to learn to use a multi-faceted ethical reasoning approach; which creates good ethical habits through continually rehearsing good responses to various common practice issues. This approach should not neglect the need for the nurse to use their ethical imagination to feel for an ethical solution. However it is appreciated that the skilled use of ethical imagination in the field of mental health nursing requires further exploration.

### **Undignifying care: An ethical dilemma experienced by relatives in home health care**

*Bente Egge Søvde (1) Gro Hovland (1) Berit Ullebust (2) Maj-Britt Råholm (1)*

*(1) Western Norway University of Applied Sciences, Førde, Norway*

*(2) Centre for Development of Institutional and Home Care Services, Sogn og Fjordane, Norway*

Developments in recent years have resulted in increased rights for those who need health care and significant changes to the next of kin's overall situation. A high quality, sustainable health care service requires that we develop policies that strengthen the cooperation between public and informal sectors and support the role of next of kin in home health care. Different directives from the government as well as National White Papers ask that next of kin play a more active role in safeguarding the quality of the patient's care. Next of kin represent an important resource for the patient, but also for the health care services. Therefore, it is important to be attentive to their situation and take their challenges with home health care seriously. Studies show that when next of kin feel supported and recognised they are able to give better support and care to their loved ones. This will in turn have a positive outcome on the health status of the patient. Paradoxically, the professional health care services are governed by financial constraints, however caring is performed in an ethical context. Thus, if next of kin are to have confidence in the health care services the care must be shown to be motivated by both professional and ethical competencies in a way that is obvious to the next of kin.

The purpose of the study is to describe the experiences of being the next of kin to a patient in home health care services. This study used a qualitative approach and latent and manifest content analysis were applied. Focus group interviews with 11 next of kin were completed in September 2016. The study was approved by the Norwegian Social Science Data Services (NSD). The results demonstrate that the next of kin experience that their situation is complex and that a great deal of responsibility for the provision of care has shifted on to them. According to the next of kin the competence of the health care staff varies substantially, and they are thus left at the mercy of the more qualified staff. The next of kin maintain that they always have to be present because they do not know if the health care personnel have enough technical skills or are sufficiently informed about the particular challenges when caring for the patients. To be able to entrust the responsibility of the patient, next of kin must be confident that health care personnel takes over that specific responsibility.

However, many find that the needs of the patients are neglected and perceive the care as undignified. Next of kin must be able to rely on health care staff to have the necessary expertise to deal with the complexities of the daily care of the patient.

### **An ethical framework for researching the bereaved**

*Maqi Sque (1), Wendy Walker (2), Tracy Long-Sutehall (3)*

*(1) University of Wolverhampton and The Royal Wolverhampton NHS Trust, UK*

*(2) University of Wolverhampton, UK*

*(3) University of Southampton, UK*

UK ethics and governance committees are tasked with the responsibility of assessing the benefits of research, proportionate to the potential for harm. Despite the development of a more integrated and streamlined approach to the review process, professional judgement is involved in the interpretation of standards for research, which can present a number of challenges for reviewers in an increasingly risk-averse climate. Individual professional judgements and an inclination to risk-averse decisions may mean investigators come across individuals or groups who act as over-zealous gatekeepers during the research process, experience variation in the verdicts of ethics committees or encounter decisions that are based on a priori assumptions. Over-cautious reactions to bereavement research can restrict access to participants or data and impose requirements that undermine the research design or in fact curb any enthusiasm to proceed with what may prove to be important work. Protection appears to be concerned with the prevention of distress to participants who are asked to recollect what may have been an emotionally challenging or traumatic event. There is however evidence to suggest that research participation may serve the interests of the bereaved in a variety of positive ways.

We present a framework for ethical decision-making for researching the bereaved that sets out practical strategies for participant identification, recruitment, data collection using interviews, and post participation follow-up care. The development of the framework was based on ethical principles that underpin research governance. The content was drawn from four studies that interviewed bereaved families of organ donors about their experiences of donating organs of a deceased relative. The practical strategies proposed in the framework were themselves exposed to ethical scrutiny, with participant and researcher evaluations determining their appropriateness. Continuing positive feedback from the use of the framework approach has contributed to its dependability in supporting ethical decision-making in bereavement research. Our team of researchers' satisfaction of working within this structure is such that it has furnished us with the confidence to offer the framework for the support of others who may be involved in the review and conduct of bereavement research.

## Indian nurses and workforce migration to Italy

*Alessandro Stievano* (1), *Gennaro Rocco* (1), *Laura Sabatino* (1), *Douglas Olsen* (2)

(1) *Centre of Excellence for Nursing Scholarship Ipasvi, Rome, Italy*

(2) *Douglas Olsen, Michigan State University, College of Nursing, USA*

**Background:** Understanding the drivers and consequences of increasing nurse migration is a priority for achieving higher quality healthcare as well as improving the working life of nurses in the globalized world (Tschudin & Davis 2008). Since the end of the 1990s Italy has had to hire nurses from overseas to fill nursing shortages. Until 2009 these emigrant nurses came mostly from other European countries, but in a changing scenario since then, and in a context of a slowing down of nurse immigration to Italy because of the economic restraints suffered in the last years, the inflow to Italy of Indian nurses is on the increase specifically from the southern State of Kerala. The substantial differences in Italian and Indian cultures prompted concern for the adjustment of Indian nurses in the host Italian society.

**Aim:** This research aimed to investigate the lived experiences of immigrant Indian nurses in Italy, specifically their professional and social integration.

**Design/Method:** A descriptive qualitative design with a purposive non-probability sample was adopted as a research strategy. This study drew on in-depth interviews with 20 Indian nurses working mainly in private hospitals. The sample comprised men and women and a range of ages to maximize the diversity. Participants spoke both Italian and Malayalam. All interviews were hand-coded line by line by the investigators. The researchers grouped meaning units with similar significance into categories and themes. Field notes were also taken of the non verbal communication of participants.

**Results:** The findings were categorised into four themes: (1) Aspects of professional integration and working experience, (2) Intra- and inter-professional relationships and perceptions of the IPASVI Regulatory Nursing Board, (3) Initial nursing education and continuous professional development, (4) Perceptions of social integration.

**Discussion:** This research offers insight into the complicated reasons for Indian nurse migration to Italy. The results showed that for Indian nurses in Italy migration meant to expand economic and social privileges as well as escape from historical assumptions of stigma associated with nursing work in India, especially for women. Participants reported some occurrences of unfairness in their work settings. However, these events seemed unrelated to ethnic origin. In Italy, where physicians still have a dominant position, especially in hospitals, to be treated with disregard is not linked to racial discrimination but to a complex set of cultural variables. Due to economic restraints, these Indian nurses, generally, did not pursue additional education after satisfying the required minimum standards. The social life of the Indian nurses was mainly associated with family or the Indian community. Indian nurses professional and social integration is not uncomplicated in the Italian society and has to be analysed in the wider socio-cultural complexities that are at the basis of transnational fluxes (Prescott & Nichter 2014).

### References

- Prescott M. & Nichter M. (2014). Transnational nurse migration: future directions for medical anthropological research. *Social Science & Medicine* 107, 113–123.
- Tschudin V. & Davis A.J. (2008). *The globalisation of nursing*. Abingdon: Radcliffe Publishing.

**From ideal somnolence to professional confidence: Nurses' role in ethical decision making for the patient**

Anne Storaker (1)

(1) *Oslo and Akershus University College of Applied Sciences, Norway*

Background: Research suggest that nurses generally do not participate in ethical decision- making in accordance with ethical guidelines for nurses. In addition to education nurses need to strengthen, their argumentation reflect on and use ethically grounded arguments and defined ethical values such as patient's dignity in their clinical work.

Objectives: The purpose of this paper is to gain a deeper understanding of how nurses deal with ethical decision making in daily practice. The chosen research question is "How do nurses regard their role in ethical decision making for the patient?"

Design and method: We use Gadamer's philosophical hermeneutics as well as Kvale and Brinkmans' three levels of understanding in interpreting the data material. Nine registered nurses were interviewed.

Ethical considerations: Approval for conducting the investigation was given from the Ombudsman of Norwegian Social Science Data and the head of the hospital. The participants received both oral and written information about the study and they gave their consent. The information included that the participation was voluntary and that they were free to withdraw at any point in the course of the study. The participants were assured that privacy, and confidentiality would be duly protected.

Results: Four key themes emerged, 1) confusion about role, 2) ideal somnolence, 3) inadequate argumentation skills and 4) pressure. Ethical ideals appear to be latent in the mindset of the participants; however, the main finding of this investigation is that nurses need to activate the ideals and apply them into practice.

Conclusion and recommendation: The participants describe a situation of being squeezed between different obstacles without succeeding in practicing their ideals. They seem to regard their role in decision-making in an ambiguous way. They would like to participate and in addition, they would like to present their views and to interfere. However, they experience too often to be unsuccessful and to fail. This repeated experience does not provide neither for self-confidence nor for growth in confidence and ambitions for the nursing role. Moreover, nurses need to work actively with self-confidence and confidence in general. Besides, the nurses seem to possess resources that are not being fully utilized. They need clear expectations for role and contribution in their daily work. Furthermore, the leadership has to initiate professional reasoning in order to activate the ideals and interdisciplinary discussions leading to common goals for patients.

## **Do cancer patients trust their nurses? A comparison of trust in nurses within cancer care across four European countries**

*Riitta **Suhonen** (1), Andreas Charalambous (2), Laurel Radwin (3), Christina Adam (4), Jouko Katajisto (5), Chryssoula Lemonidou (6), Elisabeth Patiraki (6), Katarina Sjövall (7), Minna Stolt (8)*

*(1) University of Turku, Department of Nursing Science, Turku, Turku University Hospital and City of Turku Welfare Division, Finland*

*(2) Cyprus University of Technology, Department of Nursing Studies, Limassol, Cyprus*

*(3) Boston VAMC, Boston USA*

*(4) St Savvas Anticancer Hospital, Greece*

*(5) University of Turku, Department of Mathematics and Statistics, Turku, Finland*

*(6) National and Kapodistrian University of Athens, Faculty of Nursing, Athens, Greece*

*(7) Department of Health Sciences and Skane University Hospital, Lund University, Sweden*

*(8) University of Turku, Department of Nursing Science, Finland*

Background: Trust in health care is currently high on the policy agenda, primarily because it is claimed that, for a number of reasons, public trust in health institutions and in providers is under threat. This importance is reflected in recent publications that consider trust a predicting factor in healthcare service use, part of service user evaluation of healthcare and a consequence of the patient-care provider relationship. The focus of this current study is concerned with the interpersonal trust between nurses and their patients.

Aim: The specific aims were to 1) describe the levels of patients' trust in nurses in four countries and 2) to examine differences in the levels of trust in four European countries.

Methods: This study employed a cross-sectional, cross-cultural, multi-site survey design and data were collected using the Trust in Nurses Scale (4 items on a 5-point Likert-type scale 1=never to 5 = always) in four European countries: Cyprus, Greece, Finland and Sweden. Data was obtained from patients with different types of malignancies in 17 units within five clinical sites between September 2012 and June 2014. In total 599 returned questionnaires were approved for the final analysis: Cyprus 150 (response rate 68%), Finland 158 (73%), Greece 150 (88%) and Sweden 141 (52%). Data were analysed using descriptive and inferential statistics, multivariate methods and psychometrics were also computed.

Results: The respondents perceived that they trusted nurses to a great extent. Trust in nurses was highest in Finland (mean 4.62, SD 0.43) followed by Sweden (4.57, 0.76), Cyprus (4.41, 0.66) and Greece (3.91, 0.87). The differences between the countries were statistically significant ( $p < 0.001$ , Table 1.) Differences were detected (ANOVA) between the participants from Finland and Greece ( $p < 0.001$ ), Finland and Cyprus ( $p = 0.009$ ), Sweden and Greece ( $p < 0.001$ ) and Cyprus and Greece ( $p < 0.001$ ). As the background of the participants differed slightly, multifactor analysis of covariance (country, education, type of admission, previous experiences of hospitalization, and age were used as covariates) was computed to compare the means. The model was statistically significant ( $F = 12.93$  (df 8),  $p < 0.001$ ) and country ( $p < 0.001$ ) and previous experiences of being in hospital ( $p = 0.038$ ) were statistically significant dependent variables.



Conclusions: Trust in nurses seems to be a powerful tool closely associated with relationships between patients and nurses, which may be used in nursing practice to improve patient outcomes during a nursing care episode.

### **RATIONING – MISSED CARE: An international and multidimensional problem and ethical issues**

*Riitta Suhonen (1), Anne Scott (2), Raphaela Kane (3), Evidiki Papastavrou (4) on behalf of the RANCARE COST Action WG3 and MC group*

*(1) University of Turku, Department of Nursing Science, Finland*

*(2) National University of Ireland, Galway, Ireland*

*(3) Liverpool John Moores University, Faculty of Education, Health and Community, UK*

*(4) Cyprus University of Technology, Department of Nursing, Cyprus*

Background: There is increasing evidence that the prevalence of rationing of nursing care is high in hospitals internationally and is consistently associated with negative patient, nurse and organizational outcomes. The Rationing of Care (RANCARE) Action aims to facilitate discussion about rationing of nursing care based on a cross-national comparative approach with implications for practice and professional development.

Aim: The aim of the work group 3 (ethical issues) is to encourage development of knowledge about the ethical dimensions of rationing of nursing care. The specific objectives of WG3 are:

- a) to explore the deeper moral meaning of rationing inclusive of ethical perspectives and outcomes,
- b) to facilitate discussion of the various dimensions of ethics related to rationing of nursing care and the impact on nurses (e.g. moral distress) and patients (e.g. dignity),
- c) to discuss the ethical, organisational, practical and economic aspects of zero tolerance to rationing and other alternative approaches,
- d) to discuss the implications on patients' and human rights including potential discrimination in care provision (e.g. towards particular age groups),
- e) to discuss the ethical and value principles underlying the decision-making process in clinical judgement related to rationing of nursing care
- f) to analyse the ethical dimensions of family care (care provided by family members) as complementary or replacement to nursing care due to rationing,
- g) contrasting the central values of nursing with the complex practical realities of care rationing.

Methods: The activities of the Action will be run via four working groups and two horizontal committees that will oversee the various activities planned during the four-year lifetime of the project. Each working group will focus on a different area: conceptualisation, organisational and methodological issues (working group 1); evidence-based interventions and designs (working group 2); ethical dimensions of rationing of nurse care (working group 3); educational issues and training (working group 4). Work group activities are meetings, creating networks, collecting literature, conducting literature reviews and empirical collaborative research and providing position and policy papers, organising training schools for early career researchers.

Results: Short term results of the WG3 Ethical issues will be 1) a discussion paper about resource allocation and rationing in nursing care; 2) a current state of the literature regarding ethical issues from patient perspectives e.g. patient's rights, and knowledge of missed or incomplete work; and 3) Scoping review and state of the science of priority setting in nursing and ethical issues related. The expected outcomes include advancing the knowledge of how care is being rationed, identifying ethical issues in care rationing from patients', nurses' and organisations' point of views, the factors contributing to this phenomenon, and the development of policies that aim the delivery of ethically safe care to patients.

Conclusions: This COST Action will provide greater understanding and new knowledge about ethical issues in missed or delayed care and care rationing in nursing.

### **A systematic review of ethics interventions targeted to healthcare professionals and students**

*Minna Stolt (1), Helena Leino-Kilpi (1,2), Minka Ruokonen (1), Hanna Repo (1), Riitta Suhonen (1,2,3)*

*(1) University of Turku, Department of Nursing Science, Turku, Finland*

*(2) Turku University Hospital, Turku, Finland*

*(3) City of Turku, Welfare Division, Turku Finland*

Background: Healthcare has a strong ethical basis globally and professionally. There is a need to improve and raise awareness of ethics in complex systems and in line with competing needs, different stakeholders and patients' rights. Although the delivery of ethically sound healthcare and nursing care for patients is important, there is limited evidence about how ethics in healthcare and in nursing care can be systematically enhanced with interventions in the field of ethics (hereinafter "ethics interventions").

Aim: To examine ethics interventions conducted on healthcare professionals and healthcare students to achieve ethics-related outcomes.

Methods: A systematic review design was employed. A systematic electronic search was conducted to five databases: CINAHL, the Cochrane Library, Philosopher's Index, PubMed and PsycINFO. The search was limited to studies published in English language without a time limit. The search was done with keywords: ethic\* OR moral\* AND intervention OR program OR pre-post OR quasi-experimental OR rct OR experimental AND nurse OR nursing OR health care. The search produced in total of 4,675 citations. With the four-phased retrieval process 23 full texts were included in the review. Data were analysed using conventional content analysis.

Results: Some ethics interventions were conducted among healthcare professionals and students. It seems to be possible to influence ethics of healthcare practices with different educational interventions targeted to healthcare professionals and students. All the interventions identified were educational in type. Many of the interventions focused on the ethical or moral sensitivity of the professionals, such as moral courage and empowerment. A few of the interventions were targeted to identifying ethical problems or research ethics. Interventions varied in their type, nature, conduct and dosing.

Conclusions: Patient-related outcomes followed by organisational outcomes can be improved by ethics interventions targeting professionals. However, there is a clear need to develop and implement ethics interventions in clinical practice and evaluate the effects of these interventions in the future.

### **Ethical Awareness Education for Nursing Home Care Workers in Japan**

*Masumi Sumita (1)*

*(1) University of Kyorin, Tokyo, Japan*

Introduction: This study reviews nursing home care workers' awareness of ethical issues and the current ethics education for them in Japan.

Japan is now experiencing unprecedented pressure from its rapidly aging population. This has caused an increase in the elderly who need assistance from others; hence the public long-term care insurance (LTCI) was established in 2000. During the about twenty years since the introduction of the LTCI program, the use of long-term care services has considerably grown. Long-term care services and nursing homes are important for elderly people and their families. However, serious problems caused by care workers and service providers occur, such as physical and mental abuse, provision of poor quality care, and so on. People engaged in end-of-life care services provide nursing care during a significant period of each of care recipients' terminal phase, and it is indispensable to help them develop professional ethics, and so go beyond complying with directions/guidelines and acquiring necessary assistive techniques. As care workers help activities of daily living (ADL), such as toilet support, bathing services, meal assistance and transfer, that is, they help essential activities indispensable for living. Thus, these are deeply involved in human self-esteem and dignity. In the elderly care, it is important to respect each one's self-esteem and dignity, so ethics education assumes an important role for them.

In this study, I conducted a survey to ascertain the current status of the basic education and on-site training provided to frontline care workers, as well as their awareness of ethical issues and how they may deal with them.

Methods: Mail Survey – Self-administered questionnaire in Japanese

Survey Timing –November 2015 to March 2016

Respondents Criteria – Care workers who work for nursing home in Japan

The response rate of questionnaires – 49.3%

Result: The results indicate that caregiver behavior (i.e. words used and attitude) is apt to cause problems and that tailoring care to individual elderly persons is unlikely to come along soon. The survey also revealed that ethical issues frequently arise in relation to toilet support, bathing services, meal assistance, and care recipients' safety. According to the survey, problems often remain unaddressed because care workers do not know how to deal with them and/or because regulations and established systems hinder improvement efforts.

Conclusions: Bioethics education for care workers is considered to be effective in promoting shared staff values, enhancing care quality, and deepening understanding of the individuality of elderly people. In addition to instruction in basic knowledge, many care workers also require education on

how to exercise proper judgment and solve concrete problems in the field. Therefore bioethics education has to provide care workers with concrete contents such as specific examples and discussions about how to identify problems and resolve them. It is urgently necessary that further research into ethical issues arising in the care services field be conducted and that ethics education be enhanced.

### **Promoting mhealth nursing ethical culture and decision-making capacity in care and practice in Africa**

**Ernest Tambo** (1)(2), Ghislaine Madjou (1), Adama Kazienga (3), Marcel Fogang (1), Chryseis F Chengho (4)

(1) *Africa Intelligence and Surveillance, Communication and Response (Africa DISCoR) Institute, Yaoundé, Cameroon*

(2) *Higher Institute of Health Sciences, Université des Montagnes, Bangangté, Cameroun*

(3) *Department of ehealth, Rome Business School, Rome, Italy*

(4) *Department of Health and Life Sciences, University of Coventry, Coventry, UK*

**Introduction:** Nurses and other health care providers are constantly challenged to make ethical decisions about life and death issues in providing care and counseling. Yet, little is reported on the broader context of mhealth nursing in bridging personal, societal, cultural and professional values, intercultural diversity and ethical principles, basic human rights and respect of human dignity. *The paper assesses mhealth nursing culture knowledge and practice ethical challenges, issues and perspectives in care and practice access and rights amongst vulnerable populations in Cameroon, Africa.*

**Results:** A self-administered questionnaire was designed and validated. A total of 93% response rate ( $n=224$ ), aged 27-45 years old, majorly nurses with at least 7 years nursing experiences and their patients was recorded over a period November 2016 to February 2017,. We documented that mhealth nursing care and practice, access and equity have brought ethical dilemmas to the forefront in epidemics (Ebola) and disease management (HIV and TB) in most African countries. Here, we present mhealth nursing ethical practice grounded in ethical principles compatible with patient culture and dignity (77%), quality of life (52%) and patient safety (61%). Emphasis on mhealth nursing care and practice challenges and issues bounded to right and care access, autonomy and confidentiality (82%) to collaborative participation, promotion of ethically sound informed decision (84%) in prevention, counseling and care of ill, disabled, vulnerable and dying people. The documented patient and community nursing care ethical and human rights issues included: protecting the right to live with dignity, not a right to die with dignity, ethics-related principle of autonomy and beneficence permissibility and informed consent. Fostering nursing ethical culture, direction and leadership in building mhealth ethical decision-making capacity and capability needed in delivery of nursing primary professional responsibility and care decision-making in emerging epidemics, persistent stigmatization and gender-discrimination situations.

**Conclusion:** There is an urgent need to develop and implement new and contextual mhealth nursing ethical culture and benchmarks educational curriculum and programs in promoting nursing ethics awareness and competence in care and practice in Africa context. Besides, mhealth nursing ethics

advocacy, promotion of digital nursing research is imperative in shaping health policy, personalized patient care decision making, management and education in Africa and worldwide.

### **Learning nurse students to deal with morally challenging situations in the workplace**

**Ada Ter Maten-Speksnijder (1)**

*(1) University College Rotterdam, The Netherlands*

Background: Since 2016, a new Bachelor of nursing competency framework is implemented in the Netherlands. One of the core concepts in the competency framework is the provision of self-management support with a focus on shared decision-making. Placing self-management support in the center of nursing mirrors the profession's view on good care, namely to support people to live well in spite of illness and disability. This view challenges students to develop sensitivity to patients' needs and preferences, one of the competencies within the framework, named: 'moral sensitivity'. Still, it is not known to what extent nurse students are able to understand patient's situations and what patients' needs for self-management supports are.

Aim: The aim of the study was to explore students' attentiveness for self-management support as an ethical stance.

Method: To facilitate active and reflective learning an educational tool is developed named: 'the reflective case study' (ter Maten et al., 2015). The reflective case study entails a narrative about a patient encounter and the student's reflection on it. Narratives are stories of people's lives or situations told with rich detail. After having described a situation, students closely examine and question their own decision-making process. Students consider how they could have been handled the situation differently and what other knowledge could have been brought to bear to the situation. A qualitative interpretative design was used to analyze the reflective case studies written by the nursing students.

Participants: A cohort of third year' nursing students (n=250), doing internships in a variety of healthcare settings.

Results: The findings showed that students felt stuck in situations in which patients were intensely sad or anxious. While students appeared to be moved by their patients' vulnerability, it became clear that they found it difficult to really connect with patients. When patients were angry or did not wish to follow protocols, students had difficulties to step out of their own ideas of how patients should behave. Another problem for the students was the interference of informal caregivers with alternative ideas, or the directives of clinical supervisors how to solve certain problems. In those cases, students struggled with balancing the different perspectives on patients' needs.

Conclusions: Students were attentive to the emotional state of patients in those cases in which they were able to understand the patients' feelings. When situations became complex, or patients behaved in an unexpected way, or they appeared to have different values than students, the students found it difficult to connect to these patients, and they struggled to understand their patients' needs. Nursing education has to respond to the difficulties of nursing students during their internships in order to provide them with a moral bases which is needed to become a skilled companion of chronic patients,

and support them in their self-management and autonomy.

#### Reference

Ter Maten-Speksnijder, A.J., Grypdonck, M.H.F., Pool, A., Meurs, P.L. & AL. van Staa (2015). Learning to attain an advanced level of professional responsibility. *Nurse Education Today* 35(8), 954-9.

### **How nurses describe a good death?**

*Anja Terkamo-Moisio (1), Tarja Kvist (1), Anna-Maija Pietilä (1)*

*(1) University of Eastern Finland, Kuopio, Finland*

**Background:** Nowadays most individuals die in hospitals or other health care institutions in Europe, where they are cared by nurses at the end of their lives. For example, in 2014, 65% of all deaths in Finland took place in a healthcare facility. Although nurses' important role in the End-of-Life care is widely recognized, their conceptions of "good death" are underrepresented in the literature.

**Aims:** The aim of this study was to explore Finnish nurses' varied conceptions of a good death.

**Methods:** A qualitative, phenomenographic design was carried out in this study, in order to capture the variation of nurses' conceptions of a good death. The data were collected online in April 2014 with questionnaire including an open question "How would you describe a good death?" Nurses (n=82), aged 21-65 and working in diverse settings in Finnish healthcare, completed the questionnaire. The data were analysed inductively with the "Marton method".

**Results:** The respect for autonomy and human dignity was highlighted in nurses' descriptions. Nurses described attributes such as painlessness and uniqueness to be part of their conceptions of good death. Although preparation for one's death was seen as important, some nurses considered a sudden or unconscious death to be a good one. As contextual aspects of good death nurses named a place that is valued by the dying individual. Moreover, they considered a death as good that is faced in the distant future or after fulfilment of one's lifegoals. In the nurses' conceptions presence of others was part of a good death, however, some of them stated that death should be faced alone.

**Conclusion:** The individual character of death is represented in the variety of nurses' conceptions of good death. The awareness of nurses' different conceptions of good death is crucial for high-quality end-of-life care. Therefore, the aspects of a good death need to be addressed and discussed in the nursing educations as well as in all health care settings.

### **How do nurses experience and react to sexual expressions of nursing home residents? A qualitative interview study in Flanders, Belgium**

*Kristof Thys (1), Lieslot Mahieu (1), Bernadette Dierckx de Casterlé (2), Chris Gastmans (1)*

*(1) Centre for Biomedical Ethics and Law, KU Leuven, Belgium*

*(2) Academic Centre for Nursing and Midwifery, KU Leuven, Belgium*

**Background:** Although the majority of nursing home residents continue to experience sexual needs and desires, many feel unable to fulfill them. Negative attitudes of nurses, which may reflect dominant

socio-cultural stereotypes that depict older adults as being sexually inactive, have been identified as a major barrier to residents' ability to express themselves sexually. In order to improve the sexual wellbeing and quality of life of institutionalized older adults, a more in-depth understanding of nursing staff experiences with and reactions to sexual expressions in aged care settings is warranted.

**Objective:** Our study objective is to investigate how nurses experience and react to sexual expressions from nursing home residents.

**Methods:** Our study followed a qualitative approach, rooted in grounded theory methodology. Between April 2015 and February 2016, we conducted fifteen semi-structured interviews with nurses, who were appointed in seven different nursing homes across the region of Flanders (Belgium). Data analysis was facilitated by the Qualitative Analysis Guide of Leuven (QUAGOL).

**Findings:** The nurses experienced and dealt with sexual expressions in an individual and intuitive way, which made it difficult for them to distinguish between appropriate and inappropriate behaviours. Depending on their degree of comfortness with the expressions, three types of reactions were used: (i) actively assisting residents in fulfilling their sexual needs and desires (active facilitation), (ii) ignoring or avoiding situations that might elicit sexual behaviour (passive toleration) or (iii) interrupting sexual activity by expressing disapproval or suppressing sexual arousal (elimination). Nurses' reactions were dependent upon various contextual influences, including the degree of sexual explicitness, nurses' personal experiences with intimacy and sexuality, the involvement of residents with dementia, the quality of the nurse-resident relationship, as well as the institutional culture with respect to aged sexuality.

**Conclusion:** Rather than adhering to general rules and principles, the nurses advocated a contextual approach to aged sexuality, taking as a starting point their own vulnerability as well as that of residents and family members. Our study also highlights the need for nursing home managers to stimulate an open institutional climate that supports nurses in dealing with sexual expressions. This may involve having in place a clear ethics policy, providing lifelong education about the subject matter, as well as creating opportunities for open (formal and informal) communication among colleagues.

### **A virtue-based approach to teaching person-centred care in nursing education**

*Kristin Thórarinsdóttir (1), Sigurdur Kristinsson (2), Hafdis Skuladottir (1)*

*(1) Faculty of Nursing, University of Akureyri, Iceland*

*(2) School of Humanities and Social Sciences, University of Akureyri, Iceland*

Person-centred care puts primary focus on the person rather than a specific health-condition. It emphasizes respect for individual patient preferences and values, responsiveness to patient needs and experience, communication and shared decision making. Teaching skills for person-centred care is an important goal in both medical and nursing education. However, the study of relevant nursing skills and how they are learned seems surprisingly incomplete. In nursing ethics, person-centred care may be conceptualised through nursing principles and codes, but translating these into trainable skills is a task that arguably requires a virtue-ethics approach. The aim of our paper is to address these shortcomings from the perspective of character and virtue in nursing by asking: What are the most important professional virtues and capabilities for person-centred care, and how can they be fostered within nursing education programmes?

We argued that five virtues are directly relevant: Empathy, respect, equal treatment, tolerance and the Aristotelian virtue of „friendliness“. We analysed each of these virtues based on the Aristotelian doctrine of the mean, mapping relevant emotions, perceptive skills and professional behaviours on a spectrum between vices of excess and deficiency. Our analysis incorporated the concept of *phronesis* and draws out its implications for both practical and discursive professional skills, including critical reflection on one’s own professional practice. Based on this analysis, a framework for teaching skills for person-centred care in nursing education through a virtue ethics approach was constructed and pre-tested in the Nursing Programme at the University of Akureyri. The teaching methods involved reviewing of life-story; readings and teaching of person-centred care and virtues relevant for such care; and presentation of case study in which virtues and person-centred care were intertwined. The case was discussed and reflected upon in writing.

Data collection consisted of the students’ (N=54) written reflections upon the case study. Data were analysed by directed content analysis. Preliminary analysis supports that intertwining virtues and person centred care by the respective teaching framework fosters professional development of such virtues and skills in providing person-centred care.

### **Patient perspectives on constrained patient participation in health care: A framework analysis**

*Kristín Thórarinsdóttir (1)(2), Kristján Kristjánsson (3)*

*(1) Faculty of Nursing, University of Iceland, Iceland*

*(2) Faculty of Nursing, University of Akureyri, Iceland*

*(3) School of Education and the Jubilee Centre for Character and Virtues, University of Birmingham, UK*

Patient participation (PP) is considered one of the ideals of contemporary health care. A recent critical analysis of person-centred PP in health care from patients’ perspectives showed that for such participation to be perceived as ideal, it needed to be based on patients’ experiences, values, preferences and needs in which respect and equality were central. Yet the analysis also illuminated that not all PP is ideal. Non-ideal PP was according to patients characterised by communicational struggles between patients and health care professionals (HCPs), who did not allow the kind of participation preferred by patients. We have chosen to call such non-ideal PP ‘constrained PP’. The antonym of PP, patient non-participation, has also been identified in the literature and includes such features as patients not being respected, listened to or regarded as individuals. However, the concepts of ‘constrained PP’ and ‘patient non-participation’ must not be conflated as they home in on quite different problems.

**PURPOSE:** To analyse critically attributes of the concepts ‘constrained PP in health care’; and ‘patient non-participation’ from patients’ perspectives through a review of qualitative research.

**METHOD:** Data were retrieved from data bases and analysed and synthesised according to an integrative review method and framework analysis. Sixty seven studies were included in the study. The diverse attributes of constrained PP were identified and contrasted and compared with; i) attributes of person-centred PP in health care already identified in an earlier study; and ii) attributes of patient non-participation in health care.



RESULTS: Constrained PP was understood to be not in accordance with patients' preferences for participation and characterised by lack of respect and unequal communication between patients and HCPs. First, it manifested itself through the core attribute of having to fight for preferred participation, which was then divided into the main attributes: fighting to be seen and heard; fighting for receiving information; and fighting for being involved in decision making. The second core attribute was being forced to participate more than preferred, which was then divided into the main attributes: being forced to take responsibility; being forced to take decision; and being forced to comply and co-operate.

CONCLUSION: The identification and illumination of constrained PP as a distinct problem raises the critical question if HCPs, in some instances at least, are acting in accordance with the implicit paternalistic assumption that it is in patients' best interest that HCPs determine to what extent patients should participate in their own care, regardless of the patients' preferences and wishes for participation. A paradox may lurk here: In order to satisfy the demands of anti-paternalism, some HCPs may see it as their moral duty to, so to speak, 'force patients to be free'. However, such a radical form of anti-paternalism may itself wind up as being paternalistic and disrespectful.

### **Practical wisdom in end-of-life care by general practitioners**

Guus Timmerman (1), Andries Baart (2)

(1) *The Presence Foundation, Utrecht, the Netherlands*

(2) *North-West University, South Africa*

In the tradition of empirically grounded ethics of care [1], we conducted a phenomenological, theory-oriented N=N-case study into the end-of-life care by GPs in the Netherlands. In our research, we are looking for practically proven "stepping stones" enabling professionals to deal with new moral issues. We think that what is good in care practices can be found inside care practices. Therefore, we study what participants in practices of care are doing, refrain from and are undergoing. And we install care-givers as co-researchers, with their own responsibilities. The validity and transferability of our studies are based on: the extensiveness of the cases, the rigor of the analysis, the innovative power of the developed, empirically grounded theoretical concepts and the approval the findings get from the participants in the practice researched [2]. By eliciting from GPs comprehensive case descriptions, conducting in-depth qualitative interviews about these descriptions and letting GPs participate in our research by participating in focus group interviews, the process of giving care to their sick and dying patients was reconstructed. In this reconstruction, we tried to give account of the dynamic, complex and emergent nature of end-of-life care. Our interest was phenomenological: what and how do these GPs perceive, consider, weigh, estimate, act and evaluate? To understand the process, we were forced to think complex about complex issues, to distinguish different, complementary ways of determining pain and suffering, and to develop a differentiated concept of attention. Our reconstruction resulted in a complex picture of evolving configurations of components, sometimes leading to a 'leap' into acting. To understand better this reconstruction, we referred back to the classical concept of 'practical wisdom'. In our, late-modern context, this concept has to be translated, amended and supplemented. By using a classical concept like this, we force ourselves to give account of the different context we live in now [3]. A practically wise GP – or nurse – not only knows but also actively steers on what his profession is about, accepts that he has to act, even when the ends are in conflict with one another,

the rules are contradictory and the outcome of acting is uncertain, and understands that the complexity that belongs to his profession, should not be reduced or suppressed [4].

#### References

- [1] Baart, A., & G. Timmerman. 2016. "Plädoyer für eine empirisch begründete Ethik der Achtsamkeit, Präsenz und Sorge." In *Praxis der Achtsamkeit*, edited by Conradi, E., & F. Vosman, 129-146. Frankfurt a.M.: Campus Verlag, 2016;
- [2] Timmerman, G., A. Baart & F. Vosman. 2017. "In search of good care." In *Proceedings of the European Conference of Qualitative Inquiry*, Leuven, February 7-10, 2017;
- [3] Schwartz, B., & K. Sharpe. 2010. *Practical wisdom*. New York: Riverhead Books.
- [4] Timmerman, G., & A. Baart. 2016. Ongeregeld goed: De huisarts aan het ziek- en sterfbed van de eigen patiënt [Unregulated good: The general practitioner at the bedside of his sick and dying patient]. (Research report). Utrecht: The Presence Foundation ().

#### **Euthanasia: intimate decision and fundamental right**

*Margarita Tirado (1), Yolanda Guerra Post (2)*

(1) Law school, Military University "Nueva Granada", Bogotá, Colombia

(2) Faculty of Education and Humanities, Military University "Nueva Granada", Bogotá, Colombia

Today, it is a real situation that more and more patients take the decision to finish their lives when this represents a source of pain and suffering, through a way that has earned a significant presence in human mind; this figure has originated several criticism, extreme fears, ethical dilemmas, hopes and relieves, but does not matters which have been the consequences or how that changed the vital principles in the scale of self values of each person because the deepest truth is that euthanasia belongs to the closest space, the most intimate and the most personal context of human, specially when the case involve the life and the dignity of a person who suffers an horrible and humiliating ill. Euthanasia questionates some aspects in relation with the existence: rights, religion, moral, ethics, criminal system, law, family, Government obligations and becomes in a critical situation that obligates to assume some difficult determinations but that only can be taken by the patient -and his family- without any kind of intrusion from others like the legislator, members of public forces, judges, medical staff or anyone who represents an intromision; In fact, circumstances like we are talking about, have allowed the coordinated work between sciences that usually did not to agree like law, biology, medicine, bioethics, sociology, psychology and anthropology but precisely, these knowledge want to origin opinions around the goodness or the evilness of choices related to the life, sometimes, without take into account that the 'awful monster is eating' a real life, consuming a real spirit, eliminating a real hope and killing a real project of life.

In Colombia, the Constitutional Court has been emphatic (C-239/97 y T-970/2014), through different jurisprudences, stating the "right of a dignified death" as fundamental because it is connected with life, freedom and dignity rights, the most basic rights in constitutional modern system. But in spite of initiatives of court, who expressly exhorted to Congress in order to create an special law that regulate euthanasia as a legal proceed (decision that have not been fulfilled yet by legislator) and ordered to Health Ministry to write and publish a protocol to define the process to ask for euthanasia (done in 2015) still exists several questions, distrust and anxiety between medical staff and judges. However, in

contrast to the notable lack of Colombian legislation, understood as that which comes from the Legislator (which has caused opposition and suspicion), it cannot be ignored that access to euthanasia is a source of hope and dignity of life in the Death, an urgent fact of which the Constitutional Court was aware, leaving as a single route a pair of courageous decisions and a protocol of the Ministry of Health, as a result of a jurisprudential mandate, in order to advocate for the effective exercise of freedom and the scope of a dignified life.

### **Moral distress of nurses in primary health: Advances of conceptual framework**

*Flávia Regina Souza Ramos (1), Priscila Orlandi Barth (2), Edison Devos Barlem (3), Ana Paula Trombeta (2); Carolina Caram (3); Laura Cavalcanti de Farias Brehmer (4)*

*(1) Federal University of São João del-Rei, Brazil*

*(2) Federal University of Minas Gerais, Brazil*

*(3) Federal University of Santa Catarina, Brazil*

*(4) Federal University of Viçosa, Brazil*

Moral distress is related to a situation that nurses are unable decision making according their moral judgment due obstacles. In this study moral distress is considered as a singular moral experience, once subjects become morally responsible by action. This definition was constructed by Brazilians researches in a multicentric study, which propose to construction of the scale of moral distress of Brazilian nurses. This present study was part of the multicentric research and aimed to point out advances in this scale of moral distress in the perspective of nurses who worked in Primary Health Care focus on situation which teaser moral distress as well predictors and factors associated with it. It is important theoretical advances about moral distress in Primary Health Care, considering weakness of amount of studies in this field. An exploratory descriptive mixed-method (quantitative and qualitative approach) was used to capture the complexities of moral distress. The quantitative approach was performed by applying the Brazilian scale of moral distress in 391 nurses who work in Primary Health Care in Brazil. Posteriorly, the qualitative approached was develop through semi structure interviews realized with 13 nurses who work in Primary Health Care from different regions from Brazil. The data was analyzed using Discursive Textual Analysis with support of Atlas.ti software. Together, the results make possible advances in the theoretical concept proposed focus on nurses in Primary Health Care. Overall, the results indicate that work conditions related to quality of care and nurses' autonomy were quoted as a main experience of moral distress. Further analysis showed that inadequate work conditions are obstacles to the nurses' ethical practice such as: overload, inappropriate physical space; lack of materials, equipment and human resources; and disqualified staffs. The inadequate working conditions is a trigger to experience of moral distress, once this conditions impact negatively to the quality of care because it involves recognized values such as resolutivity, integrality, ethic and humanization. So, when the result of nurses' action is inadequate, this is, the care is disqualified nurses experience moral distress because indeed they would link to provide a good care but were unable due poor conditions of work. This factor may be explain by bond between both of patient and nurses, once nurses assume a commitment to realize suitable action in an appropriate conditions. Besides that it was expressed nurses' autonomy as a reason to cause moral distress due nurses do not realize care as well they would desire. To conclude, the accountability of nurses to realize quality care is a source of moral distress when this commitment is corrupted by inadequate working conditions. The advances in

the theoretical concept of moral distress is regarding this experience also happen in Primary Health Care, once the trigger of moral distress is when nurses are able to perceive the moral problems.

Funding Statement: National Council for Scientific and Technological Development (CNPq/Brazil); - Emerging Leaders in the Americas Program (ELAP).

### **Nurses experiences of ethical challenges in the immigrant's mental health nursing**

*Tiina Tuuttila (1), Helena Leino-Kilpi (1)*

*(1) University of Turku, Department of Nursing Sciences, Finland*

Background: There are an estimated about 244 million immigrants worldwide. The immigration process, events preceding the immigration, cultural and social factors affect to the immigrant's mental health. Multi-cultural context challenges nurses to offer safe, efficient, culturally and ethically competent nursing care. At the same time European countries suffer from the nurse shortage. Supporting nurses at their work is important to them and the patient's well-being. Based on previous studies, there is lack of research in this field, especially from an ethical perspective.

Objective: Nurses' experiences of ethical challenges in the immigrant's mental health nursing will be described. Furthermore, the objective is to identify issues to support nurses' well-being when working with immigrant patients.

Methods: The study design was a qualitative descriptive study. The data were collected by focus group interviews in Southern Finland's hospital district. Four focus groups were used, based on appropriate sampling. The participants were nurses (n=10) and licenced practical nurses (n=6) having experiences to work with immigrants. The data was analyzed with inductive content analysis.

Findings: Six major categories and various sub-categories of ethical challenges were identified: (1) ethical challenges related to society (including two sub-categories: immigrant status and Finnish society, mental health services), (2) giving information (working with an interpreter and lack of a common language), (3) cultural differences (equal treatment and communality), (4) therapeutic relationship (language barrier and a different vision of care and disease), (5) nurses professional skills (nurse's ability to reflection and self-assertion, nurse's experience of dual loyalty) and (6) safety (the interaction between patients, patient's traumatic background and the patient's gender). Four categories of the issues that support nurses' well-being at their work with immigrants were identified: (1) support enabled by the employer, (2) support given by the working group, (3) the patient's well-being and functional therapeutic relationship and (4) finding the nurse's own personal limits.

Conclusion: Nurses experience a wide range of ethical challenges in the immigrant's mental health nursing. Nurses experienced that most of the ethical challenges take place on the interaction between the immigrant patient and the nurse when the nurse cannot give a good care because of practical barriers. The challenges, however, can be support to be solved with different issues. The results will help nurses, their directors, educators and students to take account ethical issues when working in immigrant's mental health nursing.

**Longing when suffering from cancer: A hermeneutic study**

*Venke Ueland* (1), *Unni Å. Lindström* (2), *Dagfinn Nåden* (3)

(1) *Department of Health Studies UIS, University of Stavanger, Norway*

(2) *Åbo Akademi University, Vasa, Finland*

(3) *Oslo and Akershus University College of Applied Sciences, Norway*

The aim of this study was to gain understanding of the existential longing related to human beings suffering from cancer. The research question was: How does longing unfold when human being live through cancer and treatment? The theoretical perspective of the study is Eriksson's theory of Caring Science. Qualitative interviews with nine women with cancer were interpreted using Gadamer's ontological hermeneutics. The findings provided access to parts of the women's unique life stories. Few events in human's life seem to be as dramatic as being diagnosed with cancer. This creates existential changes and fundamental upheaval in the individual. The study bears witness about longing, interpreted and presented through four perspectives of longing. The first perspective is related to longing as a source to call upon for survival. The second perspective is a longing for the life prior to the illness. Longing seems to be a longing that drives women to find new ground to stand on. In the third perspective there seems to be a longing directed towards deeper relations in everyday life. In the fourth perspective transcending longing goes towards the ultimate fulfillment.

Overall interpretation makes use of Eriksson's theory of caring science. Further Kierkegaard's philosophical thinking provides an additional framework. The overall interpretation leads to two dimensions: 1) Longing is becoming and movement towards reconciliation of life: 2) Longing is becoming and movement towards transcending life.

**The legal implications of the recent Court of First Instance of Leuven ruling on the refusal of a nursing home to have euthanasia performed within its walls**

*Kristof Van Assche* (1)

(1) *University of Antwerp, Belgium*

On 29 June 2016, the Court of First Instance of Leuven delivered its much-awaited verdict on the legality of the refusal, by a nursing home in Diest, to have euthanasia performed on one of its residents within the walls of the institution, even when an external physician was ready to perform it. The ruling was expected to conclusively decide one of the most contentious issues in the legal doctrine on the Belgian euthanasia law, namely whether a healthcare institution (such as a nursing home) can legally refuse that euthanasia is performed under its roof.

I will first analyse the different perspectives on a possible right of healthcare institutions to refuse euthanasia, as these have been put forward by legal scholars since the Belgian euthanasia law was first discussed in 2001. Subsequently, I will focus on the facts of the case as they were presented by defendant (nursing home) and plaintiffs (children of the lady who, following the refusal of the nursing home, was transported home to be euthanised). Finally, I will examine the verdict of the Court and its legal implications. It will be concluded that, contrary to what some experts and stakeholders have proclaimed, the court ruling does not imply that refusal by a healthcare institution to have euthanasia

performed within its walls will under all circumstances be illegal. Stating that healthcare institutions may not refuse euthanasia without providing convincing reasons, the ruling does not preclude the possibility that convincing reasons could ever be provided.

### **Evaluating home care services for the elderly: Towards a broad theoretically founded and practically applicable measure of Quality of Life**

*Myriam van Loon* (1), *Guy Widdershoven*, *R.W.J.G. Ostelo*, *J.E. Bosmans*, *K.M. van Leeuwen*

(1) *VU Amsterdam, The Netherlands*

The current evaluation of services for elderly people living at home in the Netherlands is limited, as it focuses on health in terms of functional abilities as the desired outcome of these services. Other relevant issues, such as outcomes that relate to one's quality of life – also in a state of limited health – , do not get the attention that they deserve.

The Capability Approach (CA), developed by Amartya Sen and Martha Nussbaum, can help to broaden our view on the desired outcomes of social care services, since the focus is not primarily on health, but also on other aspects of functioning. We argue that the CA puts three issues on the evaluation agenda, which all concern quality of life. First, freedom of choice. Second, prevention of adaptive preferences (people lower expectations in situations of limited possibilities). Third, the need to take into account other domains of life than health, such as human dignity.

The CA is mainly elaborated on in theoretical debates. This leaves the question how it can be operationalized in a domain such as social care and its evaluation. In the ASCOT-NL project, we will adapt the Adult Social Care Outcomes Toolkit – an instrument that evaluates the influence of care services on quality of life for older adults living at home – to the Dutch context. The ASCOT aims to measure social-care related quality of life in a broad sense. It is to be implemented both as a policy instrument – to guide allocation of resources in long-term elderly care in the Netherlands – and as a quality tool - to evaluate whether care services contribute to quality of life of older adults, and thus if the quality of care is sufficient. In this presentation we will go into whether and how the three issues put on the agenda by the CA are addressed by and operationalized in the ASCOT, and how the combination of the CA and the ASCOT can be guiding in evaluating social care for the elderly in the Dutch context.

### **Ethical Dilemma Game: Dealing with moral challenges in providing self-management support**

*AnneLoes van Staa* (1)(2), *Hester van den Bovenkamp* (1)(2), *Jolanda Dwarswaard* (1)(2)

(1) *Rotterdam University of Applied Sciences, Research Centre Innovations in Care, Rotterdam, The Netherlands*

(2) *Erasmus University Rotterdam, Institute for Health Policy & Management, Rotterdam, The Netherlands*

Background: Today, patients with chronic conditions are expected to take an active role in dealing with the physical, psychological and social demands of their disorder. To achieve optimal self-management, patients require professional support. Nurses are in an excellent position to provide such support. In a

study related to the Dutch programme Nursing Research into Self-management and Empowerment in Chronic Care (NURSE-CC), ethical dilemmas surrounding self-management (support), were unravelled, as experienced by nurses and patients. A practical guide for moral reflection on these dilemmas and an Ethical Dilemma Game were produced.

This presentation aims to:

- 1) present a brief overview of the results of the study;
- 2) involve the participants in the Ethical Dilemma Game that invites to reflect on ethical dilemmas experienced in chronic care.

**Methods:** A qualitative study was conducted among experts in self-management (n=6), nurses who provided self-management support in a variety of settings (n=15), patients with different chronic conditions (n=20) and caretakers (n=4). Experts and nurses were asked to reflect upon the concept of self-management, the underlying values and how these might conflict with other values in health care, and nurses were also asked about their experiences in providing support. The results of these interviews were used as input for the interviews conducted with patients. Respondents were contacted through the organization that provided their care. They were purposively selected on the criteria: (i) variation across medical conditions, (ii) variation across health-care settings (outpatient hospital care, home care or a combination of these) and (iii) variation in ethnic background.

**Results:** How we define self-management is a normative issue depending on the values of patients, professionals and underlying health-care policies. Differing ideas about what constitutes good care provision and good self-management present professionals with ethical dilemmas. *Nurses* faced three types of dilemmas in their provision of self-management support: (1) respecting patient autonomy versus reaching optimal health outcomes; (2) respecting patient autonomy versus stimulating patient involvement; and (3) employing a holistic approach to self-management support versus safeguarding professional boundaries. Interviewed nurses had a tendency to steer patients in a certain direction. They put great effort into convincing patients to follow their suggestions, be it making the 'right choice' according to medical norms or becoming actively involved patients.

How self-management is shaped in everyday life for *patients* partly depends on personal and social factors such as the skills patients possess, their social network and the stage of their disease. Patients views of 'the good life' are very important: *"And for me, self-management means by definition that I get to decide what is important to me, what I want to hold onto, and how I can make the little changes that let me live a reasonably normal life"*, one patient expressed. In their interactions with care professionals, clashes can arise when patients and professionals hold differing ideas, based on different values, about the level and type of patient involvement.

**Conclusions:** The discussion on self-management should account for the fact that how we define self-management is very much a normative issue. It depends on the norms and values of patients, professionals and underlying health-care policies. Differing ideas present professionals with ethical dilemmas which they should reflect on. The ethical dilemmas experienced by nurses rest on different views about what constitutes good care provision and good self-management.

Because self-management support may result in clashing values, the development and implementation of self-management support requires deliberation about the values underlying the

relationship between professionals and patients. The study produced a practical guide for nurses to embark upon such moral deliberation.

### **Providing nurse-led self-management support: From Research to Action and Reflection**

*AnneLoes van Staa* (1)(2), *Janet Been – Dahmen* (1)(3), *Ada ter Maten-Speksnijder* (1), *Susanne van Hooft* (1)(2), *Emma Massey* (3), *Erwin Ista* (3)

(1) *Rotterdam University of Applied Sciences, Research Centre Innovations in Care, Rotterdam, The Netherlands*

(2) *Erasmus University Rotterdam, Institute for Health Policy & Management, Rotterdam, The Netherlands*

(3) *Erasmus MC University Medical Center, Rotterdam, The Netherlands*

Background: Today, patients with chronic conditions are expected to take a more active role in dealing with the physical, psychosocial and social demands of their disorder. To achieve optimal self-management, patients require professional support. Nurses are challenged to provide this support tailored to patients' needs – in balance with treatment goals. Four sub-studies from the Dutch NURSE-CC program will be presented as part of the Intervention Mapping Approach: 1) interview study into nurses' attitudes and views about self-management support; 2) questionnaire study into factors influencing nurses' self-management support behavior; 3) observations of encounters between nurse practitioners and patients with different chronic conditions in out-patient settings; and 4) focus group study into the support needs of patients with renal transplantation, rheumatic disorders and head-and neck cancer. The studies resulted in the development of a new conversational tool for use during outpatient nursing consultations: the Self-Management Web.

Results: The needs assessment, part of the Intervention Mapping procedure, revealed three divergent views on self-management support among *nurses*: adhering to a medical regimen; monitoring symptoms; and integrating illness into daily life. These views differed with respect to the patient's role in self-management, the support role of the nurse and the focus of their activities, ranging from mainly biomedical to biopsychosocial. In two views, social and emotional tasks of living with a chronic condition were overlooked<sup>1</sup>. Observations of nurse consultations with patients confirmed this finding. The questionnaire study among nurses demonstrated a significant gap between self-efficacy and performance of self-management support. Nurses themselves perceived lack of time and patients' lack of motivation and competencies for self-management as important barriers for self-management support, although this was not related to their behaviour.

*Patients* indicated a need for support in developing skills for active self-management of the disorder in daily life. They wished to receive not only medical, but also emotional and social support. It is crucial for patients that this support is tailored to their individual needs. Self-management support can only be provided effectively when there is a relationship of trust between the nurse and the patient.

The newly developed intervention encourages patients to practise goal setting, action planning and pursuit skills to solve self-management challenges as assessed by the Self-Management Web. Nurses received a training in principles of Solution-Focused Based Therapy in order to develop their coaching skills, sensitize them to patients' experiences, and enable holistic support.



Currently, the intervention is being evaluated in a mixed-methods pretest-posttest study in two settings of the Erasmus University Medical Center.

Conclusions: Since self-management support should be tailored to individual patient needs, improving reflective skills of nurses and raising their awareness of patients' needs is essential. Developing interventions requires ethical deliberation about the values underlying the relationship between nurses and patients.

This presentation will give a brief but comprehensive overview of the various studies during the needs assessment phase of the Intervention Mapping procedure. This will shed light on the rationale behind the intervention and its' theoretical foundation. Attendants will be invited to comment on the intervention and share their opinions on whether and how this intervention may contribute to more person-centred care during outpatient nursing consultations with chronic conditions.

### **Letting robots through the door? Developing an experience grounded ethical account of the use of Socially Assistive Robots in aged care**

*Tijs Vandemeulebroucke (1) , Bernadette Dierckx de Casterlé (2), Chris Gastmans (1)*

*(1) Centre for Biomedical Ethics and Law, University of Leuven, Belgium*

*(2) Academic Centre for Nursing and Midwifery, University of Leuven, Belgium*

Background: Confronted with population aging and a decreasing number of (in)formal caregivers, societies are confronted with the question how to sustain dignity-enhancing care for older adults. Robot use is regarded as a plausible solution to meet the healthcare and social needs of older adults. In recent years qualitative empirical research gauging older adults' lived experiences (actual experiences, attitudes,...) with robots has gained a small rise in attention in comparison with the growth of normative literature about robot use in aged care settings. This presentation will combine and systematize the insights provided by these two discourses, so developing an experience grounded ethical account of robot use in aged care.

Methodology: This presentation will focus on Socially Assistive Robots (SARs), broadly characterized as embodied (semi-) autonomous robots with physiological assistive capabilities through the means of or alongside (rudimentary) social capabilities. Combining the results of our own review of qualitative evidence regarding older adults' experiences and perceptions of SARs use in aged care (Vandemeulebroucke et al. 2017a) and our own review of normative literature about this use (Vandemeulebroucke et al. 2017b) we propose a rudimentary experience grounded ethical account of the use of SARs in aged care.

Results: The ethical account of SARs use in aged care is normative while remaining connected to reality as it is perceived by older adults. The review of qualitative evidence identified four broad ethical issues older adults have about SARs use in aged. These issues are: a dehumanized society, privacy, autonomy and economical/financial aspects. A reflection will be done on these issues through the four approaches to ethics identified in the review of normative literature. The approaches are: deontology, principlism, capabilities approach and care-ethical approach. The reflection gives insight into the discrepancy between what already is possible in the use of SARs in aged care and the ethical reflection

about this use, the difference between ethical assessments of and the ethical reflection about SARs, and the importance of case-by-case evaluations of the use of SARs in aged care.

Conclusion: This rudimentary account of SARs use in aged care shows that one has to be aware about the distance between ethical reasoning on the use of SARs and the actual truth about their usage. Moral imagination (Anders 1956) is an important help to understand the ethical challenges new technologies pose but should not let us drift away from our current realities.

#### References

Anders, G. (1956). Reflections on the H Bomb. *Dissent* 3/2, pp. 146-155.

Vandemeulebroucke, T., Dierckx de Casterlé, D. & C. Gastmans (2017a). How do older adults experience and perceive socially assistive robots in aged care: a systematic review of qualitative evidence. *Aging and Mental Health*. DOI: 10-1080/13607863.2017.1286455. [Advance online publication]

Vandemeulebroucke, T., Dierckx de Casterlé, D. & C. Gastmans (2017b). The use of care robots in aged care: a systematic review of argument-based ethics literature. [Under review].

### **Building towards (ethical) professionalism: Making moral debate a subject in the education of care professionals/nursing students**

Els Vanwynsberghe (1)(2)

(1) *sTimul: care-ethics lab, Moorsele, Belgium*

(2) *Rhizo schools, Kortrijk, Belgium*

In this summary, we want to present some results of using the method of morel case deliberation in schools and care organisations. This practical project is a cooperation of sTimul care-ethics lab and Rhizo high schools.

Methodology: The main goal of moral case Deliberation is to support health care providers to manage ethically difficult situations in everyday clinical or school practice.

Within moral case deliberation, healthcare professionals bring in their actual moral questions during a structured dialogue. The ethicist facilitates the learning process by using various conversation methods in order to find answers to the case and to develop moral competencies. The case deliberations are not unique events, but are a structural part of the professional training on the work floor within healthcare institutions.

Outcome: teaching moral resilience: Experiences with Morel Case Deliberation are positive. Taking time to reflect with different involved professionals on the field seems very meaningful. Moral case deliberation is a source of inspiration and motivation but also determined for quality, efficiency and expediency during daily care. Some care professionals mention the experience of improvement of communication and collaboration.

Their not only use it during the one hour and a half sessions but also in daily conversations and interventions. After using the methods several times remains an attitude of listening 'passively' and starting a dialogue instead of a discussion.

**Deficit of physical and human structure in Intensive Care Unit (ICU) as a factor of intervention by judicial order**

*Mara Ambrosina de Oliveira Vargas (1), Cíntia Iara Oliveira (1), Dulcinéia Ghizoni Schneider (1), Flávia Regina Souza Ramos (1), Laura Cavalcanti de Farias Brehmer (1), Andréa Huhn (1)*

*(1) Federal University of Santa Catarina, Brazil*

Hospitalizations by court order occur when the municipality or the State doesn't have the conditions or means to guarantee an adequate assistance to the serious patient in emergency situations. In this circumstance, the family appeals to the Public Prosecutor's Office or to their lawyer to proceed or to grant an injunction, an action against the municipality and the State sent to the Central of Beds, seeking a bed of ICU. The opening of new ICU beds are increasing to serve the population. However, in Brazil, 66% of the judicial claims correspond to the attempt to access ICU beds. In its turn, the Bioethics of Protection has as its principles to analyze the capacity of protection of the physical, psychic and social integrity of the individual by the State, aiming to guarantee accountability and to act in response to situations of fragilization or threat, especially to the individuals who are vulnerable and excluded. Objective: to analyze the factors triggering hospitalization by judicial order in the ICU from the perspective of intensive care nurses in the South and Southeast of Brazil and to articulate the question of the infeasibility of ICU beds to the discussion of the Bioethics of Protection. Methodology: qualitative, exploratory and analytical research, performed with 108 nurses who work in the ICU and who experienced situations of hospitalization by judicial order. The data, collected by a semi-structured questionnaire between April 2015 and August 2016, were analyzed by Content Analysis. Discussion: in this study, the results that indicate the deficit of physical and professional institutional structure as a triggering factor of the need for hospitalization by judicial order are prioritized. Described situations with patients: coming from the interior of the contry and lack of structure and conditions of care; with polytrauma requiring a transfer to a high complexity ICU; transferred to an ICU not suitable for the treatment of their disease; which arrives from another ICU with several complications due to insufficient treatment and several sequelae (mainly nursing care); elderly patients admitted to the ICU after disclosure of video evidence of inadequate care in the hospitalization unit. The need for specialized ICU beds is due to the need for specific equipment and professionals in sufficient numbers for this type of care. The bed occupancy rate versus the nurse ratio is relevant for clinical care and a management tool related to the efficiency and costs of services. Conclusions: the judicialization culminates in actions against health institutions, often without adequate physical and professional structure to meet the demand of justice, which leads professionals to reflect on their possibilities of care, to ethical issues such as commitment to citizenship, conflicts with reality in relation to what is proposed by law, which advocates equity and universality of care. Health management encompasses the promotion of high-quality health care and care, through personnel management, input control, physical area adequacy, and technological control. Although managing the opening of new beds is crucial, there is a need for planning of the unit, human resources, services and equipment.

**What kind of perceptions and emotions do individuals have about death and post-mortem existence?**

Susanna Vatanen (1), Anna-Maija Pietilä (1), Anja Terkamo-Moisio (1)

(1) *University of Eastern Finland, Kuopio, Finland*

Background: Individuals' perceptions about death are affected by the culture, society, religious beliefs and diverse events in life. Death-related thoughts evoke strong feelings, depending of the person, whose death one is thinking about. These feelings may be distressing and influence individual's quality of life. In addition to events in life, also beliefs about post-mortem existence affects individual's perceptions of death. These beliefs are complex and include afterlife in heaven, resurrection, reincarnation and reunion with passed loved ones. Some people believe also that there is no form of existence after death, to them death presents the ultimate end. These aspects are highlighted especially at the End of Life, when encountering death becomes inevitable. However, little is known about general public's perceptions about death, post-mortem existence and the death-related feelings in Nordic cultures, in particular in Finland. The current study fills this gap for its part and provides insights to the diverse perceptions that lay people have about death and thus increases the understanding about this complex phenomenon. The produced knowledge may be utilized in the development of End-of-Life care and nurses' education. Furthermore, the results of this study may support nurses to provide more individualistic and holistic care for their patients at the End-of-Life.

Aims: This study describes individuals' death related emotions and perceptions of post-mortem existence. Furthermore, it describes how diverse events in life influence individuals' perceptions of death based on participants' narratives.

Methods: The data were collected in April 2014 with an electronic questionnaire that included the demographic characteristics and seven open ended questions regarding participants' perceptions about death and death-related aspects. The information about the study was published in a public research blog, seven discussion forums, Facebook and Twitter. In total 210 Finnish individuals participated in this study. Participants ages varied from 18 to 75 years, resulting a mean age of 42 years. They were mainly female (78%) and half of them were married or cohabitated. A small majority (54%) of the participants had children and around half (49%) assessed themselves as religious. The data yielded from four questions relevant to this study were analyzed by inductive content analysis.

Results: The data analysis is currently in progress. The final results will be presented in the Nursing Ethics conference in September 2017. The ethical aspects will be emphasized by the presentation.

**The attempted suicide: Just a cry for help?**

May Vatne (1), Dagfinn Nåden (1)

(1) *Oslo and Akershus University College of Applied Sciences, Norway*

Globally approximately one million people commit suicide. In 2015, 590 persons committed suicide in Norway (Norwegian Institute of Public Health, 2016). Persons who conduct so severe suicide attempts that they become involved in the health care systems are estimated to be 7-15 times higher than those who commit suicide (Directorate of Health, 2014), yearly estimated to 3500-7500.

The purpose of this study was to explore persons experiences based on the research question: What thoughts do persons have about the attempted suicide? The study has been carried out employing Gadamer's hermeneutics. The data is collected through research interviews with ten participants, aged 21-52, recruited from two emergency psychiatric units and one crisis resolution team at a District Psychiatric Centre. Four of them were parents to adult or minor children. Employing a thematic interpretation three themes emerged: 1) A wish to terminate the sufferings; 2) The thought of a possible repetition; 3) The shame after the attempted suicide.

The study shows that the meaning and intention of the attempted suicide might be understood differently dependent on the interpretation perspective. The attempted suicide therefore ought to be explored in the individual situation from the individual person's understanding of the attempted suicide as well as from research and expertise.

### **Paradigmatic changes in mental health in Brazil and new ethical challenges to care**

*Edilene Mendonça Bernardes (1), Carla Aparecida Arena Ventura (2)*

*(1) University of São Paulo Campus at Ribeirão Preto, Brazil*

*(2) Department of Psychiatric Nursing and Human Sciences, University of São Paulo at Ribeirão Preto College of Nursing, Brazil*

As a result of a period of great social mobilization after public disclosure of human rights violations at psychiatric hospitals in Brazil, some mental health policies emerged with a proposal of terminating with the hospital-centred model and strengthening psychosocial rehabilitation based on the respect to the rights of people with mental illnesses. This transition is characterized by several ethical challenges. Although established by the legislation, the implementation of new mental health policies is still dependent on government commitments, evidencing a dissonance between the economic decision of terminating with hospital beds and creating a network of community services. There are different and divergent interests and contradictions among mental health professionals. Within this context of paradigmatic, political and economic disputes, a group of the population lives in a situation of high social vulnerability and with no adequate care. Thus, this study aimed at analyzing the perspective of persons in mental suffering and/or their family members regarding the conditions of existence and guarantee of their rights. It is a qualitative study based on the Sociology of Absences. Data were collected through seven semi-structured interviews with nine participants who applied for the service of the Public Defenders Office at the State of São Paulo and had a demand related to mental health (three with their own demands and six with demands related to their family members). Data were analyzed through thematic analysis resulting in the following categories: (i) conditions of existence (diagnostic, violated and compulsory); (ii) experiences with the health services (course of hospitalizations; impotence and impacts; history of the extra-hospital services: the beginning of dialogue; history at the Psychosocial Care Centre); critics to the external clinics which have an agreement with the Single Health System (SUS) and to the management of mental health services. The study evidenced complex experiences of deprivations, violence at the domestic and street environments, conditions of existence (non existences, in the perspective of the Sociology of Absences), in which several human rights are violated. The references to health services point to the absence of care in the initial stage of the disease, resulting in the need for hospitalization due to the

increase of severity of most cases. The references to hospitalization are traumatic as well as the report of the lack of beds to deal with the crises. The extra-hospital services are described as the ones that enable the dialogue between professionals and families, but do not increase adherence to treatment. They emphasize the violation of human rights especially within the clinics that have an agreement with SUS and the lack of supervision of these services. Data demonstrated the need for a careful analysis about the situation of mental health in Brazil and the care provided to the vulnerable population. There are many challenges in order to assure the respect to human dignity. In the cases analyzed not only dignity is threatened but their survival.

**The contact of nursing students with the justice system: Right to health and access to justice at the public defenders office in the state of São Paulo**

Carla Aparecida Arena Ventura (1), Edilene Mendonça Bernardes (2)

(1) *Department of Psychiatric Nursing and Human Sciences, University of São Paulo at Ribeirão Preto College of Nursing, Brazil*

(2) *University of São Paulo Campus at Ribeirão Preto, Brazil*

From 2012 to the present, an extension project with nursing students at the Public Defenders Office was initiated at the University of São Paulo at Ribeirão Preto College of Nursing, Brazil. This study presents some results of this work that had the following goals: (i) to provide the opportunity for nursing students to experience the environment of an institution from the justice system that provides legal aid for the population in greater social vulnerability, learn about their health complaints and the work of the professionals from this institution to assure their right to health; (ii) to design interventions based on observation and other data collected at the institution aiming at contributing to form multiplying agents in the area of the right to health. Data were collected through direct observation, semi-structured interviews and documental analysis: (i) observation during the periods in which the professionals were attending the population at the institution site; (ii) interviews with the professionals that attended the population (five public attorneys; two professionals from the multidisciplinary team), eighteen law students who were responsible for the first interview with users and eighteen users of the services who had a demand related to health. Authors analyzed 461 records of users who had a health demand from January 2013 to July 2016. Data collected through observation gave elements to the analysis of the context and to the interviews and documental analysis. The interviews were analyzed through content analysis and the data regarding the records were analyzed through descriptive statistics. The analysis of the records identified that 72.3% of the users' ages varied from 50 to 96 years; 60% were women; the most frequent pathologies were neurological diseases (21%); cardiovascular diseases (14.7%); addictions (14.3%); psychiatric disorders (9.2%). Considering the services used by the participants: 66% were public; 22% private and 12% philanthropic. With respect to their judicial demands related to health, data showed: medication (37%); compulsory hospitalization (18.5%) and diapers (17%). The interviews resulted in the following categories: (i) characteristics of the health demands at the Public Defenders Office (domestic violence, abusive use of alcohol and drugs; compulsory hospitalization; demand for medication, diapers and treatment); (ii) extrajudicial work of the attorneys; (iii) interdisciplinary work (possibilities and difficulties); (iv) partnerships with other public services; (v) judicial work. This experience was really enriching for nursing students, as they could have a close contact with a service that has health demands but it is not their usual training site. To have the opportunity to interact with

the professionals from the Office as well as with law students and users was really important for their understanding about the complexity of the health and judicial systems. They were also able to see opportunities for greater integration between these two systems.

### **Ethical issues involving medical assistance in dying for persons with mental illnesses**

*Carla Arena Ventura (1), Wendy Austin (2)*

*(1) College of Nursing, University of São Paulo at Ribeirão Preto, Brazil*

*(2) Faculty of Nursing and John Dossetor Health Ethics Centre, University of Alberta, Canada*

In 2016, Canada legalized medical assistance in dying (MAID), transforming the public approach to end-of-life care, grounded upon values of autonomy and compassion for the suffering. There are, however, tensions and controversies associated with MAID that point to a need for continued conversation among the Canadian public. This seems especially true in regard to potential broadening of MAID legislation to encompass persons whose suffering is a consequence of mental illness. This presentation focuses on ethical issues related to MAID for persons with mental illness. Ethical issues related to MAID are characterized by questions that reflect the meaning of life and death as a sign of human finitude. Therefore, a request for MAID requires an exploration of the reasons behind the wish to have one's life ended which may reduce the freedom of the person to decide about his or her request for MAID. Given the vulnerability of people suffering from mental illness, some ethical concerns need to be taken very seriously and explored carefully. One of them is the involvement of physicians with an assessment of capacity. On the other hand, they are also allowed the option of conscientious objection. In these cases, in order to assess the patient's situation, careful diagnosis and evaluation of the patient's prognosis are of great importance. A crucial element is the psychiatrist-patient relationship and its dynamics relating to issues of hope and hopelessness. In this context, when a psychiatrist is new to the patient and has not developed this relationship, the process of decision-making is even more complex. There is clear tension between the respect for one's choice of dying and the existent lack of suitable alternatives of living a quality life in the case of persons with mental illness. Therefore, there is a thin line between the options of valorizing or sanitizing death as well as of valuing autonomy in spite of nonmaleficence, or vice-versa. The determination of legal competence plays a paramount role in the lives of persons with mental illness and will predict their opportunities of choosing their own paths of life or death. In this presentation, we argue that in the context of care, every patient's vulnerability ought to be explored and addressed by the appropriate methods and personnel, aiming at being with them in an attempt to transform anguish and suffering in an experience of integrity.

### **Nursing ethics on transplants and human rights**

*Huige Li (1), Silvio Verbeek (2)*

*(1) Department of Pharmacology, Johannes Gutenberg University Medical Center, Mainz, Germany*

*(2) Doctors Against Forced Organ Harvesting, Washington DC, USA*

Nurses have a vested interest in human rights, and according to their codes of ethics, act as benevolent leaders for the best interest of patients and other vulnerable persons.

In the field of transplantation, nurses promote information and education on the donation of blood, tissues and organs, and support people involved in donating and receiving. Having the ability to make people think and be sensitized is commonplace in the complex health care environment of organ transplantation and organ procurement.

In this context it is a responsibility to the victims to be knowledgeable about unethical practices that are widespread in China today, to have access to ethical guidelines and be prepared to offer safety and ethics information to patients and families who are considering transplant tourism to China.

The breach of commonly agreed to voluntary and altruistic organ donation in China has been happening for over the last three decades. As patients in need of transplant organs travel to other countries as transplant tourists in search of rapid pay-to-order treatment, unethical forced organ harvesting has gained global attention and condemnation.

Over 90% of the organs transplanted in China before 2010 were procured from prisoners. International ethical guidelines clearly state that prisoners, deprived of their freedom are not in a position to guarantee free, voluntary donation, and it cannot be guaranteed that coercion by the prison system is not involved. Prisoners of conscience are not convicted criminals. For their belief, prisoners of conscience are persecuted, detained, tortured and medically monitored in prisons and re-education camps in China. They make up a living organ donor bank for China's lucrative transplant industry. Renowned for the health benefits of their spiritual practice, Falun Gong adherents especially are reportedly the primary organ source, with minority Uyghurs, Tibetans, and House Christians also subject to this atrocity.

Although in December 2014 Chinese officials announced that the country would completely cease using organs harvested from prisoners, no regulatory adjustments or changes in China's organ donation laws have followed. Ignoring global condemnation, China has re-defined prisoners as "citizens" who, by virtue of their citizenship, have their right to "voluntarily" donate organs as free people do in other countries. This is in violation of WHO, and all other governing medical authorities. Of urgent concern is that China, despite extensive evidence from international sources, has not publicly admitted to exploiting prisoners of conscience, does not allow any transparency, and is not cooperative in ensuring that ethical standards are met. This makes any announcement made in 2015 to end the killing a hollow promise.

### **Back to basics: A systematic experiential learning process supports Advance Care Planning (ACP)**

*Karen Versluys (1), Ruth Piers (1), Liselotte Van Ooteghem (2), Gerda Okerman (3), Linus Vanlaere (4)*

*(1) Department of Geriatric Medicine, Ghent University Hospital, Ghent, Belgium*

*(2) GVO (Group of Nursing Homes for Elderly), Courtrai, Belgium*

*(3) Palliative Care Network Gent-Eeklo, Belgium*

*(4) Catholic School Association RHIZO, Courtrai, Belgium*

Introduction: Advance care planning is too often limited to legal documents with advance directives. The phenomenon of pseudo participation may occur. Based on the right to self-determination people make choices without knowing what really is at stake. Only in life threatening situations, people seem to realize the meaning of these conclusions and make choices different than the advance directives they described earlier. ACP has to be a process of dialogue about desirable 'end of life'-scenarios with



all relevant stakeholders before life threatening situation occur. Therefore the aim of this project was to set up and evaluate a new educational initiative for health care providers (HCP). In this systematic experiential learning process (SELP), HCP learn the necessary skills to actively listen and hear what the patient really values.

Intervention and methodology: Twelve nurses in hospital, nursing home and home care setting participated the SELP which consisted of an open interview with a patient and a reflection process among participants. All interviews and discussions held as part of the SELP were recorded and transcribed. The data were analysed qualitatively using methods of Grounded Theory and using data and researcher triangulation.

Results: Patients/residents are thankful to be able to tell their story. Getting the opportunity to tell their story to an attentive HCP leads to a relationship of trust in which there is openness and safety to talk about patient's values.

Most participants realize that open conversations from person to person, help to better know the patient and what is at stake for this patient leading to a better relationship with the patient. The analysis showed that most participants are able to have an open conversation with a patient concerning ACP. Although participants describe having fear that the conversation will not be good enough, they succeed as soon as they let their fear go. Also the patient-oriented vision of care and the climate of reflection of the team in which the participants work, seems to influence the success of this process. A team familiar with reflection, supports participants in having an open conversation with the patient that ensures a relationship of mutual recognition and involvement leading to more attunement in care.

Having an open conversation with a patient is the first step, which has to bring participants to ACP-interventions focused on patients' needs. Discussing the obtained information in team and translating it into care objectives needs further attunement. Conclusion: The SELP supports participants in having an open conversation with a patient concerning ACP and hearing what really is at stake for the patient.

### **Ethical and cultural striving: Lived experiences of minority nurses in dementia care**

*Egede-Nissen Veslemøy (1), Gerd Sylvi Sellevold (2), Rita Jakobsen (2), Venke Sørli (2)*

*(1) Oslo and Akershus University College, Norway*

*(2) Lovisenberg Diaconal University College, Norway*

Background: Nursing' workforce in Western European health institutions has become more diverse because of immigration and recruitment from Asian, African and East-European countries. Minority health care providers may experience communication problems in interaction with patients and co-workers. They are likely to experience conflict or uncertainty when confronted with different cultural traditions and values. Persons with dementia are a vulnerable group. The consequence of their illness challenges the ability to understand and express oneself verbally. The large number of MHCPs in nursing homes underline the importance to obtain better knowledge about this group's experiences with the care challenges in dementia care units.

The aim: of the study was to explore and examine MHCPs lived experiences with challenges in caring for persons with a dementia.

Research design: We used a qualitative method, conducting individual interviews, using a narrative approach. In the analysis, we applied a phenomenological hermeneutical method, developed for researching life experiences.

Participants and research context: five MHCPs in a nursing home, in a dementia care unit.

Ethical considerations: The study is approved by the Norwegian Regional Ethics Committee (REK) and the Norwegian Social Science Data Services (NSD.) All guidelines for research ethic were followed.

Results: The results show that MHCPs are striving to understand the quality of care for persons with dementia. This striving consists of a sensitivity to understand the person's verbal and nonverbal expressions, to understand the gratefulness, to understand the person as an adult and autonomous person, and to understand the person as a patient in a nursing home. Challenges comprise both ethical and cultural striving to understand quality of care to persons with dementia.

Conclusion: To care for persons with dementia in an unfamiliar context may be understood as a striving to act ethically, and at the same time striving to adapt and acculturate to new cultural norms in order to perform quality dementia care

### **Making nurses and other health professionals in dementia care able to be better professionals**

*Kari Vevatne (1)*

*(1) University of Stavanger, Norway*

Aim: Making nurses and other health professionals in dementia care able to be better professionals

Background: Working in a nursing home with dementia patients can be challenging. Often days characterized by routines for both professionals and for patients and it can be difficult to keep the ethical standards at a high level. This study will challenge this by providing teaching and reflection on ethical theory to meet the ethical issues that one can encounter in practice. This can be studying and training on through learning *to see* the patient. It mean to the theoretical study of vision ethics and then work in practice. To train with roleplay and practice for personal who are employed by nursing homes and who work daily in dementia care.

Method: Theory lessons will be given in order to studying Soren Kierkegaard through a series of lectures totaling 6 hours and then create roleplaying situations in order to train to meet patients in different situations where Kierkegaard's existential ethics forms the basis. Roleplaying will take place in parallel with theoretical instruction. The training program will be offer for a group of eight participants, who have signed up for the program. The selection will be random. The program will be oral and written evaluated after the program is finished.

**Ethical issues in bereavement research: Practical use of a decision-making framework**

Wendy **Walker** (1), Magi Sque (2), Tracy Long-Sutehall (3)

(1) University of Wolverhampton, UK

(2) University of Wolverhampton and The Royal Wolverhampton NHS Trust, UK

(3) University of Southampton, UK

There are many phenomena in nursing that fulfil the criteria of sensitive research. Sensitive research has been defined as research that poses an intrusive threat, explores an intensely personal experience or has the potential to arouse an emotional response. The central concern being the possible threat it poses to participants and researchers that could be both physically and mentally distressing. Without doubt bereavement fulfils the criteria of a sensitive research topic that demands careful planning in the design of a study, to assess the ethical issues involved, and to ameliorate the risk of harm.

This paper adds to the discourse concerning ethics in bereavement research. It demonstrates the practical use of a framework for ethical decision-making when undertaking research with bereaved participants. We contextualise the framework and issues of ethical importance through presentation of a qualitative, exploratory, interview study with bereaved families who consented to organ and tissue donation from a deceased relative. The sensitive nature of the study is illustrated by providing an overview of participants' descriptions of a critical event that led to a sudden bereavement.

Practical strategies of relevance to the processes of: participant recruitment, the interview encounter and follow-up care in the post-interview period are illustrated and discussed. Concerns about the possible repercussions of bereavement research are balanced with the views of family members who gave credence to the therapeutic and cathartic benefits of taking part in sensitive, death related research. Through our research with bereaved families, we are privileged to offer acceptable standards for research ethics and governance, of value to the community of nurses involved in bereavement research.

**"It hurts": Student and novice nurses providing palliative and end-of-life care**

M.E.A. van Sasse van IJsselt (1), M.A.R. Boonstra (1,2), E.J.M. Bakker (1)(3), S. Stout-Kerstjens (2), C.M. Dekker – van Doorn (1), Erica Witkamp (1)(2)

(1) Rotterdam University of Applied Sciences, Rotterdam, The Netherlands

(2) Erasmus MC Cancer Institute, Rotterdam, The Netherlands

(3) VU University Medical Centre, Amsterdam, The Netherlands

Introduction: Providing palliative and end-of-life care is complex and is difficult to cope with for nurses, especially for nurse students and novices. They are at increased risk for distress during internship or as a novice at a clinical ward for palliative care, when compared to other care settings. Knowledge of the risk factors and the supportive interventions is of importance to prevent preliminary drop-out. We studied the impact of providing palliative care, and the needs and opportunities for support of students and novice nurses.

Methods: At the Rotterdam University of Applied Sciences, faculty of nursing, and the Erasmus MC Cancer Institute Rotterdam, department of Medical Oncology, the Netherlands we provided (1) a

literature study; (2) explorative qualitative research (a narrative analysis, a focus group discussion and interviews) in clinical practice, and (3) a quantitative study among a purposive sample of 39 third year nurse students, using an adapted version of the Rotterdam MOVE2PC questionnaire (MOVE2PC-s). This instrument includes 20 knowledge statements, and three vignettes assessing 18 potential difficult situations on palliative care.

Results: Providing palliative and end-of-life care is emotionally burdensome for novice nurses. They highly empathize with the patients, including their grief and sorrow. More negative than positive emotions were reported. Most reported in literature and in practice were distress and psychological pain. Workload and caring for both palliative and curative patients are important risk factors for drop-out. During internships students rarely discussed their experiences with palliative care and corresponding feelings, thoughts, and emotions, which contributed to distress. Literature, and students and novices raised supportive needs, for which various interventions were suggested. Each of these meet some of the supportive needs, but none meets all. According to the literature and respondents, intervention and the palliative care companion (PCC) programme seem the most promising and feasible interventions. In their third year, half of the nurse students reported to have cared for dying patients during previous internships, while feeling insufficiently prepared. Nine out of 20 knowledge statements were answered correct (SD 2.3), and a mean of seven (SD 2.9) out of 18 difficult situations were reported. Students reported a need for more education in palliative care.

Discussion and conclusion: The literature study and the qualitative and quantitative studies showed that providing palliative care is an emotional rollercoaster for student and novice nurses. They feel inadequately trained, prepared, and capable when confronted with patients at the end of life. Furthermore, they have poor knowledge on palliative care, and they show unhealthy behavior while feeling intense involved in the patients' situation. More palliative care courses during the initial nursing education programme may improve students' preparedness to palliative care. In addition, in clinical practice some interventions may trigger behavioral change and improve novice nurses' resilience. Preparing student and novice nurses to the complex and emotionally intense palliative care requires various interventions, in which faculties of nursing schools and departments in clinical practice should collaborate to prevent preliminary drop-out of nurse students and novices.

### **How about autonomy? The role of relatives in the care for patients dying in the hospital**

*Erica Witkamp (1)(2)(3), Mirjam Droger (3), Rien Janssens (4), Lia van Zuylen (2), Agnes van der Heide (3)*

*(1) University of Applied Sciences, Rotterdam, The Netherlands*

*(2) Erasmus MC Cancer Institute, Rotterdam, The Netherlands*

*(3) Erasmus MC University Medical Center, Rotterdam, The Netherlands*

*(4) VU Medical Centre, Amsterdam, The Netherlands*

Introduction: Hospital care and communication tend to be focused on the individual patient and the decision-making is typically based on the principle of individual autonomy. It can be questioned whether this approach is adequate in terminally ill patients, as many patients want a close relative to be involved in decisions at the end of life. The aim of this study was to investigate the experiences of relatives concerning their role and position during the last days of the patient's life in the hospital.

**Methods:** The study was embedded in a retrospective questionnaire study on the quality of dying of a consecutive sample of patients who died in a university hospital in the Netherlands (2009-2012). 451 relatives of 951 deceased adult had completed the questionnaire. We performed a qualitative analysis of the comments and answers of relatives to open questions.

**Results:** Relatives expressed a need for 'comprehensible, timely and sensitive information and communication', 'involvement in decision-making', 'acknowledgement of their position', 'being able to trust healthcare staff', and for 'rest and privacy'. When relatives felt that their role had sufficiently been acknowledged by healthcare professionals, their experiences were more positive.

**Discussion and conclusion:** These themes largely match with one of the eight dimensions of patient-centered care, i.e. 'involvement of family and friends', including providing accommodation for relatives, involving them in decision making, supporting them as caregivers, and recognizing their needs and contributions. In the care for patients dying in the hospital relatives have an important role. An approach of healthcare professionals to care that is exclusively based on individual patient needs and autonomy seems inadequate. The role of relatives might be better addressed by the concept of relational autonomy, which creates opportunities to involve relatives in providing patient-centered care and adequately addresses the needs of patients.

### **End-of-life Moral Distress among Nurses: Where does Moral Resilience Fit?**

*Krista Wolcott (1)*

*(1) Sonoma State University, Rohnert Park, California, USA*

A theoretical and conceptual analysis of moral distress through the lens of moral resilience as a way to interpret research findings and guide future practice. Consideration of latest recommendations around developing and supporting moral resilience of nurses, acknowledging the complex relationship between individual nurse empowerment and moral distress levels, highlights the importance of considering environmental influences on the individual nurse moral distress experience. Incorporating a systems approach with individual development reflecting cultural components offers a deeper understanding into moral distress and the potential role of moral resilience. End of life care is commonly associated with moral distress, and various strategies have been suggested to assist with alleviation of moral distress in this setting. Cultural perspectives, individual perceptions of role and obligations of care, and varying environments of care settings all contribute to moral distress experiences, and potentially to moral resilience. This paper reflects the examination of moral resilience from the theoretical perspectives of Critical Realism, Transcultural Nursing, and Uncertainty in Illness theories; and seeks to better understand moral resilience and its potential impact on experience of moral distress among those caring for dying patients.

### **Palliative care nurses' viewpoints on euthanasia: Reflections on a New Zealand survey**

*Martin Woods (1), Helen Rook (2)*

*(1) Victoria University of Wellington, New Zealand*

*(2) Victoria University of Wellington, New Zealand*

As has been commonly experienced in several countries, attempts have recently been made in New Zealand to introduce legislation that supports euthanasia in the form of 'Assisted Dying,' or 'Physician Assisted Suicide.' These attempts have intensified considerably in recent times, characterised by intensive lobbying and national debate fuelled by High Court declarations, a Voluntary Euthanasia Society petition to Parliament, Health Select Committee investigations, and a Private Members Bill.

A predominant feature of the public debate in New Zealand debate is the way in which it is automatically assumed that euthanasia legislation, were it ever to be passed, would naturally and logically involve nurses and/or doctors as gatekeepers and agents of delivery. In part, this is based on recent surveys that, although nurses' specific viewpoints have never been fully explored, have suggested that many nurses (and doctors) in New Zealand are seemingly supportive of the idea of legislative change regarding euthanasia. However, such surveys are not without controversy and dispute, and subsequently the findings are often criticised and open to interpretation.

Yet it is reasonably apparent that nursing opinion on euthanasia varies considerably, i.e. the Palliative Care Nurses of New Zealand (PCNNZ) position remains that "... assisted dying in any form is incongruent with the underlying ethos and practice of palliative care and nursing", whilst the New Zealand Nurses Organisation has taken a different viewpoint, i.e. generally supporting legislative change in favour of euthanasia. Regardless, any views of New Zealand's palliative care or hospice nurses on the topic had until recently been unknown as no research had been performed with such nurses in New Zealand.

In the first instance, this presentation offers the main findings of a small survey that the authors recently performed to ascertain the viewpoints on end-of-life issues (including euthanasia) of palliative care nurses working for three New Zealand hospices. These findings are of considerable interest and are not without some controversial aspects (e.g. the release of the findings was subject to permission being obtained from the three hospices).

Secondly, it also offers reflections concerning the overall design and value of such surveys, difficulties involved in interpreting the findings, and the politics and pragmatics associated with disseminating the results.

Consequently, this presentation should be of interest to all nurses involved in end of life care, and especially to palliative care nurses. These findings should also be of considerable interest to nurse ethicists and educators in other countries where euthanasia legislation either already exists, or is being considered.

### **A nursing ethics perspective on palliative sedation**

*David Kenneth Wright (1) Chris Gastmans (2), Amanda Vandyk (1), Bernadette Dierckx de Casterlé (3)*

*(1) School of Nursing, University of Ottawa, Canada*

(2) *Centre for Biomedical Ethics and Law, University of Leuven, Belgium*

(3) *Academic Centre for Nursing and Midwifery, University of Leuven, Belgium*

Palliative sedation is a practice in end-of-life care that involves reducing or eliminating a person's consciousness in order to alleviate their suffering, when that suffering is considered refractory to any other intervention that is possible, available, and tolerable. Recently, the ethics of palliative sedation have come under scrutiny in certain legislative arenas. For example, laws in the Canadian province of Quebec and in France now establish a positive legal right to receive palliative sedation as one therapeutic possibility in end-of-life care. Elsewhere and around the world, practice guidelines typically frame palliative sedation as an acceptable end-of-life care option. The practice however gives rise to much attention in clinical ethics literature, where authors focus on such concerns as moral distinctions between palliative sedation and assisted death, questions of proportionality, and issues around the meaning of suffering and how best to respond.

As for any end-of-life care practice, nurses are heavily involved in the care of people who are considering or receiving palliative sedation. We know from available research that palliative sedation is an important source of moral concern for nurses. In order for nurses to be supported in providing ethical care for people who request and receive palliative sedation, and to mitigate challenges to nurses' moral experiences of end-of-life care, we require a clear, coherent, and robust ethical understanding of palliative sedation from a nursing perspective. Does such an understanding exist?

This presentation will discuss a review of argument-based nursing ethics literature about palliative sedation. This method adapts a systematic review procedure to identify all existing non-empirical papers in which authors discuss the ethics of a particular topic and offer a normative position in relation to that topic. Our goal is to analyze the current state of moral discourse about palliative sedation within nursing literature, ultimately seeking to discern whether and to what extent a nursing ethics of this practice exists. Our ideas around what a nursing ethics might mean are informed by theoretical notions of moral identity and moral agency in nursing. Our review thus looks to the existing literature that focuses on palliative sedation from a nursing perspective and asks what values, responsibilities, and ideals for good nursing care are reflected in this literature.

We analyzed our sample of included literature by asking three questions: 1. What definitions of palliative sedation are emphasized? 2. What normative meanings of palliative sedation are apparent or argued for? 3. How are nurses' moral identities and/or moral agency portrayed? In this presentation we will discuss the results of our analysis, and identify some suggested areas where nurses could further contribute to a nursing ethics of palliative sedation.

### **The effectiveness of structured class debate on teaching ethics for undergraduate nursing and midwifery students in Brunei Darussalam**

*Yusrita Zolkefli (1)*

(1) *University Brunei Darussalam, Brunei*

The teaching of nursing ethics aims to enhance nurses' personal and professional values, and therefore able to respond to ethical dimension in practice. Despite various strategies of teaching ethics, many studies report positively that debates are an effective way to introduce complex and contentious issues into teaching. The aim of this paper is to reflect and evaluate on the use of structured class debate in

the teaching of ethical issues to undergraduate nursing and midwifery students in Brunei Darussalam. A series of class debate with 2 hours contact with student peers and facilitator were conducted for 17 second-year nursing and midwifery students. During the debate, the students bring in their ethical understandings in a structured dialogue. This paper presents the underlying theory on teaching ethics and illustrates the use of class debate as the central pedagogical approach, along with lectures at the outset. The effectiveness of class debate was first evaluated using the module evaluation where students' reflect on their learning experiences in the preparation and implementation process of class debate. The effectiveness was further evaluated where the author shares experiences in the design of ethics module, implementation process and implications of class debate on students' development of moral competencies in writing ethics assignment. Based on this evaluation, the author postulates that whilst class debate increases students' learning and understanding of ethical issues, its effectiveness entails a consistent reflection of ethical discourse both in the classroom and clinical settings.