

PRISMA project – clinical research priorities in end-of-life (EOL) patients

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PRISMA project (Positive DiveRsities of European PrIorities for ReSearch and Measurement in End of Life CAre) has been launched by European Association for Palliative Care (EAPC) and is financed by European Union. Prof. Richard Harding is a coordinator, while prof. Irene Higginson is a scientific project leader (of King's College, Great Britain). Participating countries from EU are Belgium, Italy, Netherlands, Germany, Portugal, Spain and Great Britain, while associating countries are Norway and other invited countries.

PRISMA is a three-yearly project divided in 8 thematic parts. The theme of the third workshop was clinical research priorities in end of life patients („Clinical research priorities in end-of-life care (EOLC)“. Workshop leader was prof. Stein Kaasa. I was invited to the three day workshop at St Olavs University Hospital in Trondheim (Norway) to present the state of palliative care in Croatia.

The work was divided in two groups: the first had the task to analyse clinical priorities and the framework for future research, and the second had to identify the barriers and solutions for research in EOLC.

It is very important to research the patients in terminal

phase of life, regardless of whether the research is voluntary or professional, because with the given data we can establish:

- Whether current care is fulfilling the need of the patient and his/her family in end of life situation?
- Do we have to change our medical approach?
- Is there a better method to provide care?
- Can we prove the need and the significance for different type of care?
- Can we analyse the current type of care?
- Also, can we pinpoint the area where terminal patient doesn't have support and we can make a strategical plan for changes?
- The base for financing (HZZO, other foundations)
- The changes in health politics of the country in question

It is extremely difficult to research in palliative care. As we are actually analysing the approach – i.e. 'palliative care' – we discover that this is not easily measurable. Usual points of research, has the patient 'survived, cured' are not applicable. The outcome is dead patient, and exhausted and sad family.

Members of PRISMA team in Trondheim



Other striking problem is to define the group research – and who is the subject of interrogation. As in palliative care we consider the patient and the family to be the center of our treatments, it is necessary in our research to include the patient and the carer (usually a member of the family). Also, as in different countries, i.e. in Great Britain, Croatia and Uganda, in the end of life care we encounter different customs, so it is not possible to apply the same questionnaire without prior alterations.

There are different barriers identified in the research of EOLC, regardless the fact that we are considering countries with developed or insufficiently developed palliative care. Most common barriers are: lack of funding, difficulties in applying multicentric studies, insufficient education for research and uneven ways of measuring.

Provided solutions are: international research, using same ways of measuring (Palliative care outcome scale - POS), and including time for scientific research into normal working

hours. Also, based on collective work, we should agree the WHO's directions for palliative care and EOLC.

Next phase of the PRISMA project will be focused on research and analysis of the most applicable questionnaire for EOLC. Two questionnaires have been agreed upon: Palliative care Outcome Scale (POS) and Support Team Assessment Schedule (STAS). They are concise, they include both the patient and carer, and they are easily repeated. They are filled in by patient, his/her carer or a member of palliative team. Following our agreement with R. Harding, we are adapting the questionnaires to Croatian culture and tradition.

Participation in a team which very intensely and creatively researches palliative care was a big acknowledgement to Croatian volunteers for our work in organizing palliative care. But at the same time, it felt uneasy to be the only representative, from all the participants, of a country without a single institution for palliative care.



University hospital Sent Olavs in Trondheim



Group work with Irene Higginson (on the right)