# FOR IN-C

## EXPLORING THE DETERMINANTS OF THE EXPERIENCE OF CARE

### FOR IN-CENTER HEMODIALYSIS PATIENTS:

### SURVEY FROM ONE LARGE PRIVATE DIALYSIS NETWORK IN ROMANIA

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#### OBJECTIVES

Improvement in outcomes for chronic diseases needs a holistic approach addressing not only the technical aspects of medical care but also the governance of care provision and the strategies for gaining adherence to the constraints of a chronic illness in a cost-effective manner. Changing the patterns of care provision towards a real patient-centeredness which involves genuine patient-caregiver partnership and patient is a challenging task. The aim of the Experience of Care working-group from IHS was to analyze the elements of care that in-center hemodialysis patients value most, in order to develop policies addressing their needs.

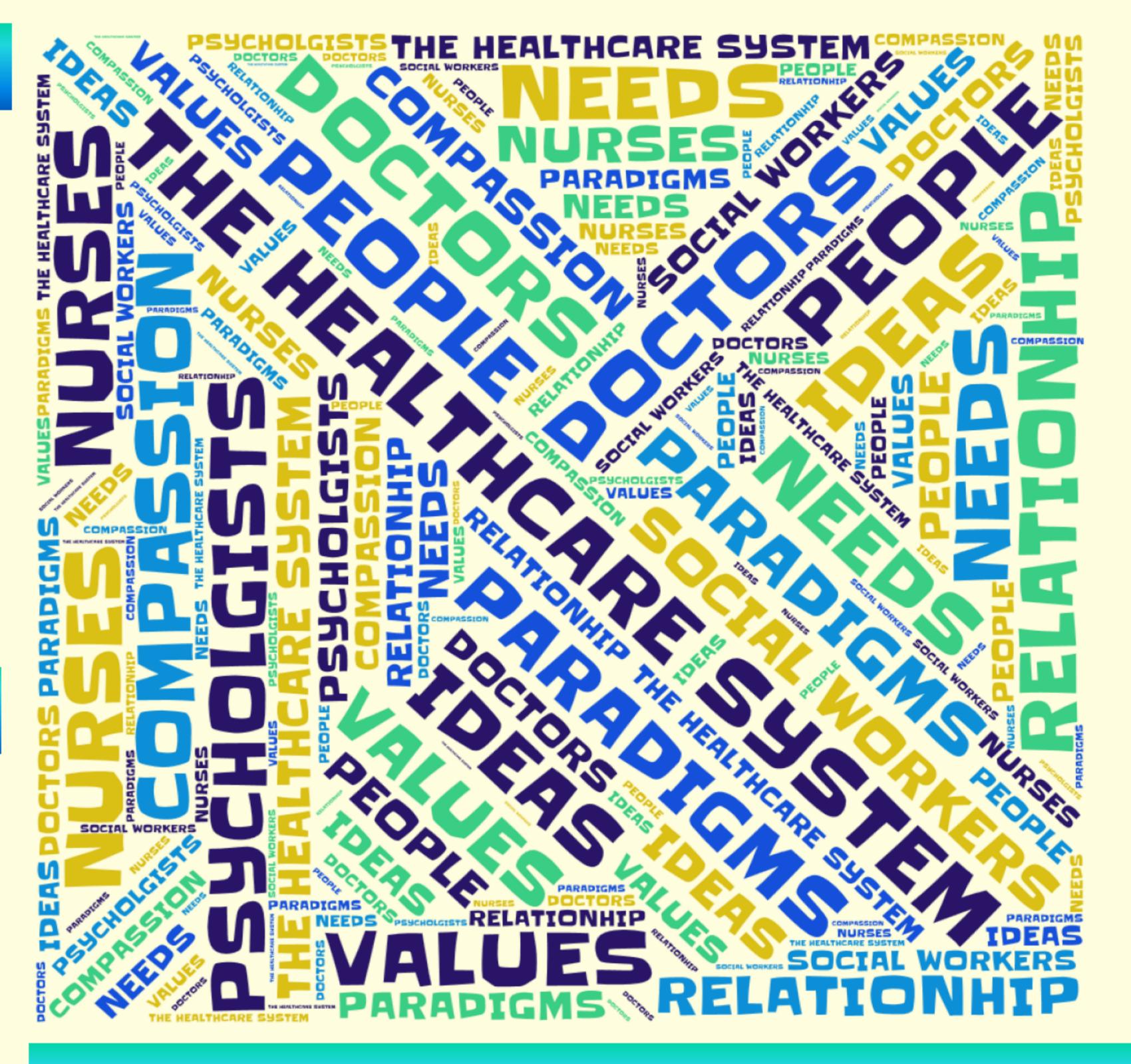
#### METHODS

A cross-sectional survey was performed during the month of July 2014 by means of a questionnaire among 327 patients randomly selected out of the 1327 patients undergoing in-center hemodialysis in the 13 dialysis units from the network.

The questionnaires were elaborated by the multidisciplinary group of experts (senior nephrologists, dialysis nurses, clinical psychologists experienced in working with dialysis patients, education specialists, quality and operational managers) and a five-point Likert scale was used to rate each item in the questionnaire. The internal consistency of the questionnaire was assessed using Cronbach's alpha statistic, the alpha value obtained for these data was 0.655, which was thought by the group of experts as being fair enough for this exploratory survey. The questionnaire was completed with a second part, in which the subjects were asked to choose from a list the 5 most important items for defining the excellence of care.

Demographic data was collected for each respondent, which included sex, age, education level, dialysis vintage, and place of living. The subjects were invited to grade by the personally perceived importance various aspects of the in-center hemodialysis care (treatment, staff, communication and relationship, infrastructure, operational issues, additional services (transportation, catering, etc.), as well as related attitudes and behaviors.

In order to better serve the exploratory scope of this survey, we performed the analysis using the Bayesian network modeling and data mining functions of BayesiaLab Professional Edition 5.2 software.



#### RESULTS

Answers were obtained from 292 patients, but only 278 questionnaires were valid, which gives an error margin of 5 at a 95% confidence level. The mean age of the respondents was 58.66±13.52 years with a gender distribution of 50.4% females vs. 49.6% males. 56.1% came from urban areas. The mean duration of dialysis was 4.71 years, with a SD of 3.96.

The most striking result was the inverse correlation between the valued items: "professionalism", "efficient treatment" on one hand and "care", "kindness", "warmth of the heart" on the other, suggesting a perceived dichotomy between the technical part of medical care and the more humane attributes of it, that could originate whether in the culturally induced perception on the medical staff or in the lower level of health literacy that doesn't enable the respondents to evaluate that technical part. These groups are almost identical in size (49.3% vs. 50.7%). The group of subjects favoring the humanistic component of care has a lower education level and resides more frequently in the rural area. This group value more the services from less specialized staff, is less interested in getting information about the disease and grades higher additional services like catering.

#### CONCLUSIONS

Moving from the authoritative model of healthcare to the collaborative one which favors proficient therapeutic relationships between the patient and the caregiver has to deal not only with the paradigms of the healthcare system, but also with the patients' beliefs and understanding, which are undoubtedly influenced by the level of health literacy and the societal practices and culture. Unveiling and addressing the real care needs, expectations management and health education programs should be considered for attaining this goal.

#### SPECIAL THOUGHTS GO TO:

- P E Teschan
- D G Oreopoulous S Shaldon
- B H Scribner
- K Nolph
- D N S Kerr D J Kolff

And so many others, including those in the picture







