



Patient-centered outcomes: Quality of life concerns reported by patients undergoing dialysis

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46th EDTNA/ERCA International Conference | Krakow | Poland | 9-12 September 2017

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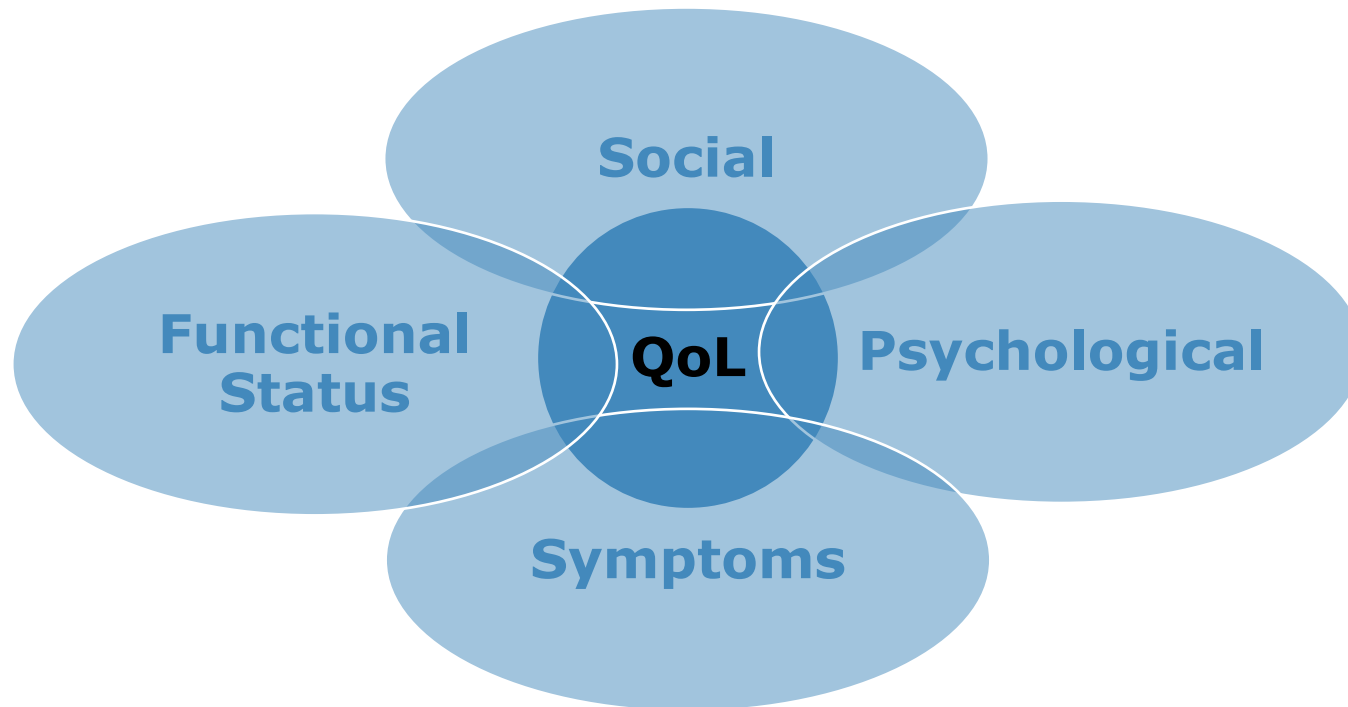
Introduction (1/4)

- The diagnosis of a chronic disease is a negative life changing event having physical, psychological and social consequences and the initial news of a life-threatening condition is often devastating for patients;
- Major life changes, by definition, require individuals to cope with a new set of life circumstances;
- ESRD affects all aspects of life:
 - Social and family relationships;
 - Economic well-being;
 - Activities of daily living;
 - Recreational and professional activities [1]

Introduction (2/4)

- The chronic disease as a stressor, i.e. the way it is perceived by the person and the strategies used to face the new health situation, can be reflected in their well-being and Quality of Life (QoL) [1];
- QoL is a subjective measure of the perceived effects on health and the ability to cope with life [2];

Health-related QoL comprises four basic domains



[3]

Introduction (4/4)

- Chronic diseases have to be managed instead of cured;
- Maximising patients' QoL is an important outcome in healthcare [4];
- ESRD patients undergoing dialysis represent an elderly population often suffering from multiple diseases requiring several treatments that may interact and interfere with their QoL.

Objectives

- To evaluate how patients' life changes and how dialysis affects their quality of life;
- To assess the range of patient-relevant outcomes in patients undergoing dialysis, using an individualised measure that allows patients to indicate their main concerns.

Methods

- Cross-sectional study with ESRD patients on regular dialysis three times a week;
- Patients completed the Psychological Outcome Profiles (PSYCHLOPS) [5].

PSYCHOLOPS

1.

1.1. QUAL O PROBLEMA QUE MAIS O PREOCUPA?
(Por favor, escreva na caixa que se segue)

"A doença... ^é ainda o que me preocupa mais e sinto-me mal e não pode..."

Results (1/3)

- The study was conducted with 97 ESRD patients on regular dialysis in our clinical center:
 - 39.2% males;
 - 60.8% females;
 - 69.86 ± 14.03 years old
- Analysis of 156 answers.

Results (2/3)

Physical health symptoms
25.6%

- "I feel tired, I cannot keep my balance very well climbing a ladder"

Family
16.0%

- "Fear of not being healthy enough to take care of my children"

Autonomy
13.4%

- "I can not go to the bathroom myself anymore"

Domestic tasks
12.2%

- "I can not take care of the house anymore"

Treatment
9.6%

- "Being here is like being in prison"

Results (3/3)

Work
7.7%

- “Not working during dialysis”

Loneliness &
death 5.2%

- “Staying home alone”

Others
10.3%

- “I get bald”

Conclusions

- ESRD patients on dialysis perceive their wellbeing as being affected by a broad range of non-clinical factors, and survival is one of the less reported issues, as compared to other domains;
- These results reinforce care guidelines that recommend that treatment programs should not only address survivorship or biological outcomes, but also psychosocial adaptation to the disease [6];
- In this population, QoL assessment and care should include the family dimension. Managing the negative impacts of both disease and treatment within the family is one of the most important priorities in the treatment of ESRD patients.

**Thank You Very Much
for Your Attention!**

Acknowledgments

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