CONFEREncE ABSTRACT

Measuring Caregivers Experience: design and results of IEXPAC Caregivers
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An introduction comprising background and problem statement: The role of caregivers of people suffering one or more chronic conditions has been analyzed and established, but there are no tools to measure their experience as caregivers with health and social professionals and services in a cost-effective manner. Subsequently, efforts to improve it may result uncertain. There is a need to have a validated instrument to assess caregiver experience.

Theory/Methods: We adapted IEXPAC to measure the experience of non-professional caregivers of people suffering one or more chronic conditions. IEXPAC is a validated scale that measures patient experience ref ICIC, www.iexpac.org. IEXPAC defines patient experience as the information that the person facilitates on what has happened to her in her continued interaction with the health and social care professionals and services and on how she has lived that interaction and its outcomes.

This is an observational study that applies discussion group technique to a random selection of 8 non-professional caregivers 67 year-old average, 16 year of experience as caregiver of a family member, with Alzheimer in 5/8 , mental disorder in 3/8 and EPOC in 2/8 of the cases to adapt IEXPAC questionnaire. The resulting caregiver questionnaire was administered to 122 caregivers of similar profile.

Results: 10 out of 16 items got 5/5 points in comprehension of the statements. All responses were in the 2,3- 5 range. In two items, small modifications were proposed and accepted to improve clarity. Caregivers considered that the explored dimensions addressed he most relevant aspects of their experience as caregivers average of 5 points. The 5 step Likert scale never to always was considered easier 5/8 than the completely agree to completely disagree scale 3/8. 7/8 respondents consider the filling in paper facilitated response while 2/8 did the same with filling in internet. Experience with health and social integrated care was assessed by 122 caregivers referred to coordination and continuity of care among all the implied professionals, respect to values and preferences, support to improve care competencies,
address caregiver stress and overload, use of new technologies to facilitate interaction, and commitment to improve wellbeing.

**Discussions:** The highest challenges needed are related to support to improve care competencies and the use of new technologies to facilitate interaction.

**Conclusions comprising key findings:** The measurement of caregivers experience might contribute to improve integrated care by incorporating the emotional, informational and personal needs of the people who assume the care of chronic patients. IEXPAC caregivers is an instrument that joins acceptability, easiness of use and utility perceived by the own users.

**Lessons learned:** Caregivers feel relieved and reassured in their role as feel they are taken into account by health services.

**Limitations:** Older caregivers tend to positive assessments.

**Suggestions for future research:** The social networks sites could be modified the caregivers experience of loneliness and relief.

**Keywords:** integrate care; caregivers; patient experience; quality assurance