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'Family level dementia care assessment tool': a tool to assess Quality of care received by dementia patients in Sri Lankan setting

Jayakody SN[1], Arambepola C[2]

[1]Department of Community Medicine, Faculty of Medical Sciences, University of Sri Jayewardenepura, Sri Lanka; [2]Department of Community Medicine, Faculty of Medicine, University of Colombo, Sri Lanka

Background: Dementia has become a public health priority along with population ageing worldwide. In the absence of a cure, maintaining the best possible quality of care (QOC) has become the desired outcome for people with dementia.

Objectives: To develop a multi-source tool to describe QOC received by patients at family level

Methods: The tool development process was consisted of five steps; item generation, item reduction, formulating the draft tool, translation and finalization. A qualitative study was conducted. Interpretative phenomenological approach was applied to identify items for the tool based on current quality care recommendations, using triangulation of techniques [in-depth and key informant interviews (KI) and focus group discussion (FGD)]. KI were consultant psychiatrists, neurologists, psychiatric social workers and consultant community physicians. In-depth interviews were conducted with patients and FGDs with the caregivers. Purposive sampling was done. Number of interviews was decided on data saturation. Item reduction was done through modified Delphi technique. The tool was translated to Sinhala language and finalized after assessing judgmental validity (face, content and consensual validity).

Results: The newly developed 'Family level dementia care assessment tool' comprised of 56 items under 7 themes to be used as a multisource tool (observations on home environment, interviews with patient and caregiver). The main themes in the tool are home environment, primary caregiver, availability of a care plan, types of activities in practice, interpersonal relationships, availability of social network and patient's appearance and behaviour. The tool has demonstrated acceptable level of face, content and consensual validity.

Conclusions: 'Family level dementia care assessment tool' can be used as an observational checklist even by a grass root level health care worker, to assess the family level care received by dementia patients. This preliminary data on family level dementia care can be used to sensitize policy makers and also to plan interventions towards improving QOC among dementia patients.

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