

Including informal caregivers in decision making regarding the treatment of neuropsychiatric symptoms in dementia

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Introduction

- Approximately 60% to 90% of all patients with dementia are affected with neuropsychiatric symptoms (NPS)
- Although non-pharmacological interventions are advocated as initial treatment, prescription rates of psychotropic drugs (PD) that can cause serious side effects, are still high.
- Informal caregivers can play an important role in interventions that prevent occurrence or escalation of NPS.
- Despite the importance of involving informal caregivers, it is not yet clear in what way informal caregivers are involved in decision-making regarding treatment of NPS (see figure 1).

Methods

- Face-to-face in-depth interviews with 10 quadruplets (physician, psychologist, nurse and informal caregiver connected to the same patient with severe dementia living in a nursing home)
- Participants were interviewed separately to prevent socially desirable answers
- The interview focused on the most recent decision regarding:
 - the start/stop of a prescription or
 - adjustment of the dose of a PD or
 - use of non-pharmacological interventions
- The data was thematically analyzed

Objectives

- to get an overview of the decisional process regarding treatment of NPS from perspectives of both professionals and informal caregivers
- to get information from the perspectives of all stakeholders involved

Results

There was some involvement of the informal caregiver in most cases, but the involvement does not reach the level of shared decision making. From this the following themes emerged: 1) signaling, 2) discussing options, 3) decision-making, 4) barriers/facilitators involvement

Phase 1: Signaling

In most cases (6), participants believed that the *nursing staff* signaled the problem behavior and brought up the behavior during consultations with other professionals.

Phase 2: Discussing options

In all cases but one, there was a consultation between physician, psychologists and nursing staff. to discuss the problem behavior. In all but one case the informal caregiver was not present. Two informal caregivers were invited to those meetings. However, one caregiver preferred meetings solely with the physician.

Role (N=10)	Mean age	Gender
Patient	77 (59-94)	Female 5 Male 5
Physician*	46 (29-60)	Female 6 Male 4
Psychologist	38 (26-60)	Female 7 Male 3
Nurse	40 (23-49)	Female 9 Male 1
Informal caregiver	56 (26-82)	Female 8 Male 2

*3 nurse practitioners, 7 elderly care physicians

Phase 3: Decision making

In two cases the informal caregiver (spouse) was just informed about the decision. In six cases the professionals made the treatment decision and proposed only one treatment option to the informal caregiver without giving any alternatives. In two cases the physicians discussed the treatment options with the informal caregivers.

Professionals mentioned they wanted to increase the contact with informal caregiver or involve them at an earlier stage. Furthermore professionals perceived shared decision-making as the ideal decision-making model, although they had doubts about how to implement shared decision-making in practice.

Barriers/facilitators towards informal caregiver involvement

Professionals mentioned the following barriers (informal caregiver did not mention any barriers):

- Involving the informal caregiver in the decisional process costs time
- Including the informal caregiver delays the decision-making process
- Fear to overburden informal caregivers.
- Informal caregivers have to bring up reasonable arguments
- A critical family is experienced as difficult

Facilitators mentioned by professionals and informal caregiver:

- Informal caregiver can provide important information about the patient
- Informal caregiver is frequently visiting the nursing home.
- Critical informal caregivers increase amount of communication
- More involvement improves the quality of the decision

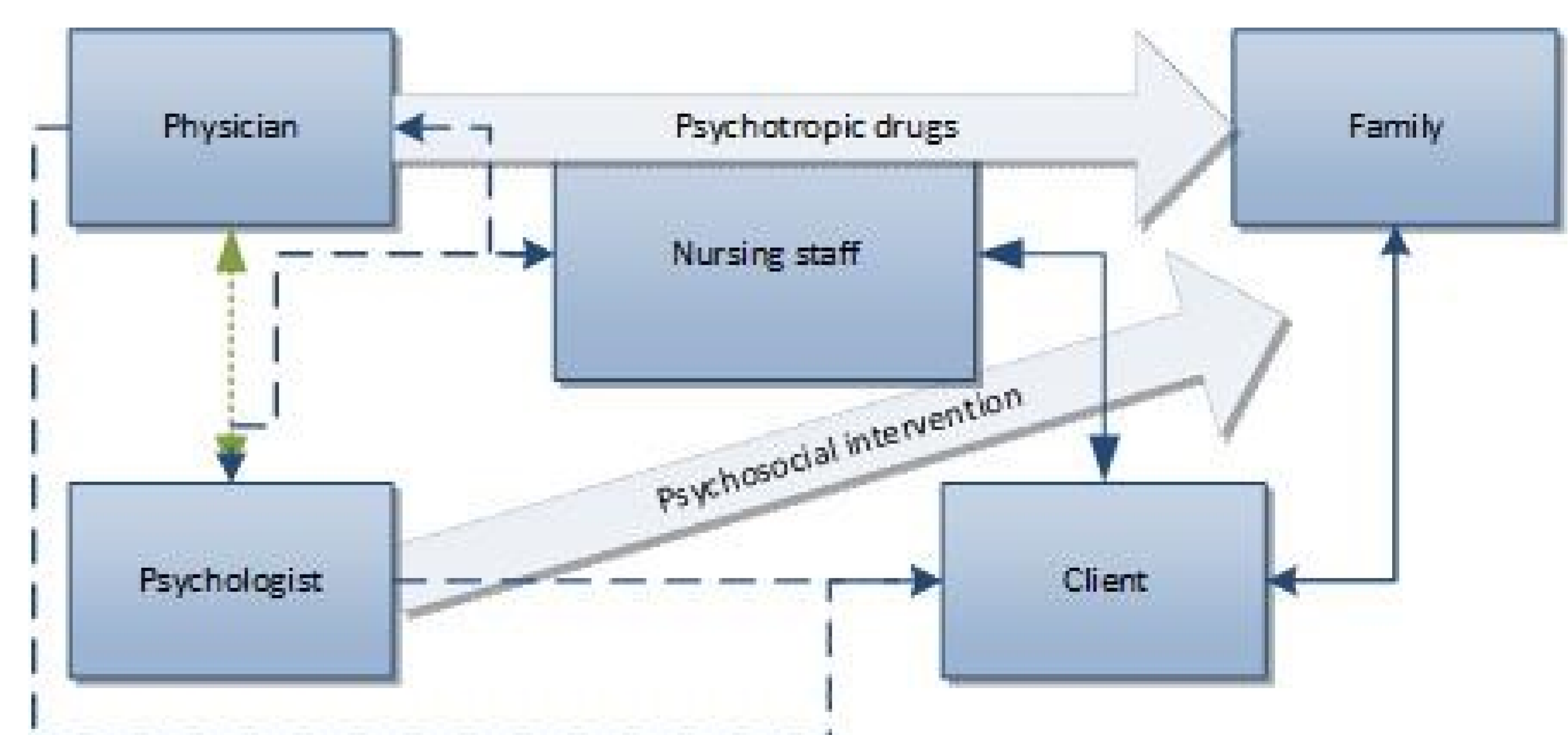


Figure 1: Interplay between client, health care professionals and informal caregiver in the medical decision process

Discussion

- The current study showed that there was some involvement of the informal caregiver, but the involvement does not reach the level of shared decision making.
- More caregiver involvement is needed and wanted by professionals
- It is advised to involve the informal caregiver in an earlier stage to explore treatment options in consultation with the informal caregiver.
- Additionally future research with a larger sample size is needed to confirm the results of the current study.