Study on preferences and care options among older people living in nursing home

Submission date 16/05/2016	Recruitment status No longer recruiting	 Prospectively registered Protocol
Registration date 20/05/2016	Overall study status Completed	 [] Statistical analysis plan [X] Results
Last Edited 25/09/2017	Condition category Signs and Symptoms	Individual participant data

Plain English summary of protocol

Background and study aims

An advance directive (AD) is a living will, a legal document in which someone specifies what health treatment they should be given if they become unable to make decisions for themselves or communicate their wishes to others at a later date. However, programmes (or interventions) to promote Ads have only been partially successful and has too often been addressed in the context of resource allocation for professionals to the detriment of a holistic approach, that is one including patients and close relatives. To change this requires focusing on patients' priorities according to their specific values and wishes. Advance Care Planning (ACP), centered on patient and family perspectives, pursues that goal. The aim of this study is to develop and test the feasibility, acceptability and effectiveness of a ACP nursing intervention to help with discussions about care priorities and healthcare decisions at end of life.

Who can participate?

People aged 65 or over with close relative, newly admitted in nursing home.

What does the study involve?

The study intervention includes ongoing discussions and decision-making processes involving nursing home patients, close relative and experienced specially trained nurse. During the course of three sessions, the nurse and patient discuss the patients personal needs, values and beliefs about end-of-life with the help of a card game. The nurse then repeats the process with the patients close relative, but this time the relatives is predicting how the patient would respond. Similarities and differences between the answers given by the patient and their relative is hen discussed, along with any possible implications for the future care and treatment of the patient. All participants are assessed on their care preferences, their perception of how well they communicate their wishes for end-of-life care with the nurse and thoughts on how this may affect the close relative before the start of the study and then 3 months later.

What are the possible benefits and risks of participating?

Possible benefits include starting discussions about end-of-life care with the support of a specialized nurse in a sensitive approach. Focusing on values and priorities, interviews favor personal expression and three way communication. There are no risks for participants

Where is the study run from? Five nursing homes in Geneva (Switzerland)

When is the study starting and how long is it expected to run for? September 2010 to December 2012

Who is funding the study? School of Health Sciences - Geneva (Switzerland)

Who is the main contact? Professor Laurence Séchaud laurence.sechaud@hesge.ch

Contact information

Type(s) Scientific

Contact name Prof Laurence Séchaud

Contact details Avenue de Champel 47 Genève Switzerland 1206 +41 (0) 223885642 laurence.sechaud@hesge.ch

Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers 11-043

Study information

Scientific Title

Effect estimation of an innovative nursing intervention to improve Advance Care Planning among nursing home's residents and their relatives : a pre-post pilot trial

Study objectives

To develop a new Advance care planning (ACP) nursing intervention and test its feasibility, To evaluate the acceptability, faisability and potential effects of an innovative ACP intervention with nursing home résidents (NHRs) and their close relatives.

Ethics approval required Old ethics approval format

Ethics approval(s) The Human Research Ethics Committee of the Canton of Geneva, 25/05/2011, ref: CER: 11-043

Study design Interventional non-randomised study

Primary study design Interventional

Secondary study design Non randomised study

Study setting(s) Other

Study type(s) Quality of life

Participant information sheet

Not available in web format, please use contact details to request a participant information sheet

Health condition(s) or problem(s) studied

End of life care for elderly in nursing homes

Interventions

The Advance care planning (ACP) intervention includes ongoing discussions and decision-making processes individually and within the dyad with the support of an experienced nurse trained in the ACP intervention. The specificity of the intervention consisted of three interviews and the use of an alternative card game called "Go Wish".

This game is composed of 36 cards, each of which presents a statement that refers to personal needs, values, and beliefs about end of life care. First, instructions to NHRs are to sort (very, medium or low importance) the cards in three piles, then select the ten most important, rank them according to their personal priorities and discuss the reasons for their choices. Secondly, the close relatives follow the same process but on their predictions about NHRs' choices. Finally, the dyads discuss similarities and differences in choices and the implications of the identified priorities for future NHRs' care and treatment.

Intervention Type

Behavioural

Primary outcome measure

Feasibility defined as Ability to enroll and retain dyads

1. Number of participants, close relatives recruited; timepoint: end of recruitment (31/05/2012) 2, Number of dyads retained after intervention (patients, close relatives); timepoint: six months

after end of recruitment (31/11/2012)

3. Distribution of the intervention (integrity and fidelity) patients records; timepoint: six months after end of recruitment (31/11/2012)

4. Adherence to data collection plan; patients records; timepoint: six months after end of recruitment (31/11/2012)

Acceptability

5. Acceptability of the intervention for patients, close relatives; Satisfaction questionnaire; timepoint: T2= 3 months post intervention

6, Acceptability for nurses delivering the ACP intervention in terms of fidelity, resources mobilized and practice change. Satisfaction questionnaire; T2= 3 months post intervention

Secondary outcome measures

1. Quality of end of life communication with the nurse (NHR & close relative) measured with the "Quality of Patient-Clinician Communication About End of Life Care (QOC)"; timepoint: T= pre intervention (5-6 weeks after admission) and T2 post intervention (six months after admission) 2. Congruence in preferences and care options (dyad) measured with the «Statement of Treatment Preference (STP)» Timepoint: T1= pre intervention (5-6 weeks after admission) and T2 post intervention (six months after admission) and

3. Perceived Burden (close relative) measured with the "Brief Burden Interview " (BBI) Timepoint: T1= pre intervention (5-6 weeks after admission) and T2 post intervention (six months after admission)

Overall study start date

27/09/2010

Completion date

21/12/2012

Eligibility

Key inclusion criteria

1. Newly admitted in nursing home

2. ≥ 65 years old

3. Suffering from a chronic disease with a potentially fatal outcome, or from a life-threatening disease

4. Mentally competent

- 5. Fluent in French
- 6. Have a close relative who agreed to participate in the study

Participant type(s)

Mixed

Age group

Senior

Sex Both

Target number of participants

Minimum 40

Key exclusion criteria1. Serious cognitive impairment2. Already written ADs3. Significant motor and/or sensory deficits

Date of first enrolment 15/05/2011

Date of final enrolment 31/05/2012

Locations

Countries of recruitment Switzerland

Study participating centre House of Petit-Saconnex Retreat (Maison de Retraite du Petit-Saconnex) Avenue Trembley Geneva 12-1209

Study participating centre Val Fleuri Geneva Switzerland 1206

Study participating centre Vessy House (Maison de Vessy) Geneva Switzerland 1234

Study participating centre La Petite Boissière Residence Geneva Switzerland 1208 **Study participating centre Charmilles Residence** Geneva Switzerland 1203

Sponsor information

Organisation Leenaards Foundation (Switzerland)

Sponsor details Rue du Petit Chêne 18 Lausanne Switzerland 1003 +41 (0) 21 351 25 55 fondation@leenaards.ch

Sponsor type Research organisation

Website http://www.leenaards.ch/

ROR https://ror.org/004h88r69

Funder(s)

Funder type Not defined

Funder Name School of Health Sciences - Geneva (Switzerland)

Results and Publications

Publication and dissemination plan Results manuscript ready for submission

Intention to publish date 20/06/2016

Individual participant data (IPD) sharing plan

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	results	01/06/2014		Yes	No