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

Submission date
16/05/2016

Recruitment status
No longer recruiting

Registration date
20/05/2016

Overall study status
Completed

Last Edited
25/09/2017

Condition category
Signs and Symptoms

[_] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[X] Results
[_] 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?
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Contact information

Type(s)
Scientific

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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)
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 criteria
1. Serious cognitive impairment
2. Already written ADs
3. 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
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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