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Perceptions/experiences of end of life care for those living with/supporting those living with respiratory disease

Submission date
25/05/2022

Recruitment status
No longer recruiting

Registration date
14/06/2022

Overall study status
Completed

Last Edited
10/06/2022

Condition category
Respiratory

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] Record updated in last year

Plain English summary of protocol

Background and study aims

We live in a world where advances in medical treatments, an ageing population and increasing expectations have led to patients once considered to be too high risk for surgery now being operated on routinely. In addition to this, treatments for life-threatening conditions have given the medical establishment the ability to prolong life. Specifically, within the field of respiratory care the advancements in the management of an acute exacerbation of a chronic disease have resulted in significant changes in patient outcome.

For patients, as well as their families, the decisions surrounding the final phase of their medical management are often distressing and information and discussion regarding the end of someone's life can shape how the care at the end of life is ultimately provided. In several studies, patients want more information regarding their diagnosis and its prognosis in order to facilitate participation in decision making. However, significant work is still required if the ethos of patient participation in end of life decision making is to be realised as laid down in the End of Life Care Strategy.

However, not all patients are found to be proactive, engaged, or even aware of their condition this may be due to the belief that they are unable to be helped. Ultimately, this results in more patients with conditions such as chronic obstructive pulmonary disease (COPD) needing more urgent care for their symptoms and therefore often requiring hospitalisation. It is possible that diseases which include a very variable trajectory, such as COPD, may facilitate confusion and uncertainty for patients, their families and staff, and therefore, for the care and education that is provided. It is suggested that this complex trajectory will impact upon the staff experience of the patients' death as well as the care provided and may inadvertently result in caregivers feeling unprepared and unsupported.

The complexities of long-term respiratory disease and its difficulties associated with its trajectory as well as the medical establishments' ability to prolong life also appear to have raised questions regarding how information is provided to patients and their families. The variabilities in trajectories are based on pathophysiological changes and psychological changes as well as cultural and social differences in patient groups.

The overall aim of this study is to explore the experiences of three different groups in relation to end of life care and non-malignant respiratory conditions. The key objectives for this study

relate to the exploration of specific experiences/perceptions of the participants. These objectives are the exploration of:
1. The experience of the care/information received whilst living with a non-malignant respiratory condition
2. The experience of the care/information received specifically regarding end of life care related to the condition
3. The experience of the care/information received whilst caring for someone living with a non-malignant respiratory condition
4. The experience of the care/information received specifically regarding end of life care related to the condition the individual was/is living with
5. The perception of the care/information given to patients at the end of life
6. The experience of working with patients at the end of their life from a non-malignant respiratory disease
7. What additional information (for example educational package, informative literature) would be beneficial.
The three groups are patients, carers or relatives and staff and they will be viewed equally. This sets it aside from current research which either looks at two of these groups, not all three, or seems to make the assumption regarding the different roles the participants will take. For example, staff will only have an opinion as a clinician in relation to the clinical management of the patient rather than have an individual experience that needs to be understood or patients or carers may have an experience that is only to be understood from a passive perspective rather than someone who could be equally involved in healthcare choices.
This study will therefore, provide knowledge and a greater understanding of the patient, family /carers and staffs' experiences and perceptions when living with, or working with patients with, a non-malignant, but incurable, diagnosis. From this perspective it may highlight gaps in knowledge that need to be addressed relating to the education and information provided to families and patients as well as the staff working with these patient groups.

Who can participate?
1. Patients with a long term, progressive, non-malignant respiratory disease
2. Individuals who are supporting, or have supported, someone living with/lived with a long term, progressive, non-malignant respiratory disease
3. Nurses in primary care (practice) who are supporting, or have supported, someone living with /lived with a long term, progressive, non-malignant respiratory disease

What does the study involve?
Individual semi-structured interviews are carried out to discuss the participants' experiences of the management of long term, progressive, non-malignant respiratory disease

What are the possible benefits and risks of participating?
The risks related to inconvenience of the time of the interview. In order to limit this, interviews were carried out, where feasible, at a time and place convenient to the participant. The benefits related to providing a voice to those participants who are interested in the topic and feel they have important and valuable information to share

Where is the study run from?
University of Hertfordshire (UK)

When is the study starting and how long it is expected to run for?
February 2012 to October 2015

Who is funding the study?
University of Hertfordshire (UK)

Who is the main contact?
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Contact information

Type(s)
Principal investigator

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
128138

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
IRAS 128138

Study information

Scientific Title
Family, patient and staff perceptions and experiences of end of life care for those living with a non-malignant progressive respiratory condition

Study objectives
The prevalence of non-malignant respiratory disease across England and Wales is increasing with chronic obstructive pulmonary disease (COPD) alone expected to be the third-highest cause of

mortality by 2030 (NICE 2010). A national consultation has been carried out (Department of Health 2010) on the care and support offered to patients specifically with COPD. The national consultation has highlighted a variety of areas where further work is required to improve the equity of care (Department of Health 2010). One such area of inequity relates to end of life care and information for patients with COPD. NICE (2010) guidance has stated that palliative care for patients with a non-malignant related respiratory disease should be available from the point of diagnosis. However, this does not appear to happen in the clinical arena (Department of Health 2010). COPD has a very unclear prognostic pathway and therefore issues arising from variable disease pathways, such as psychological, emotional and social concerns may be more extensive in this patient group. In turn, this may facilitate confusion and uncertainty for staff, and therefore, for the care and education that is provided. Therefore this study will aim to explore the perceptions and experiences of end of life care for those living with a non-malignant progressive respiratory condition, those working with them and their families.

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 17/12/2013, NRES Committee East of England - Norfolk (Nottingham REC Centre, The Old Chapel, Royal Standard Place, Nottingham, NG1 6FS, UK. This is now the merged East of England - Cambridgeshire and Hertfordshire REC, Health Research Authority, 2 Redman Place, Stratford, London, E20 1JQ, UK; +44 (0)2071048096, +44 (0)207 104 8102, +44 (0)207 104 8265; cambsandherts.rec@hra.nhs.uk), ref 13/EE/0384

Study design
Qualitative research design using semi-structured interviews

Primary study design
Observational

Study type(s)
Quality of life

Health condition(s) or problem(s) studied
Non-malignant progressive respiratory disease

Interventions
Individual semi-structured interviews are carried out to discuss the participants' experiences of the management of long term, progressive, non-malignant respiratory disease.

Intervention Type
Other

Primary outcome(s)
The participants' experiences of the management of long term, progressive, non-malignant respiratory disease, measured using a qualitative interview with each participant at least 5 years post the commencement of their involvement with this condition. The data from these interviews are analysed using thematic analysis including interrogation of the data, coding and development of themes

Key secondary outcome(s))

There are no secondary outcome measures

Completion date
19/10/2015

Eligibility

Key inclusion criteria
1. Individuals living with a non-malignant progressive respiratory condition
2. Individuals supporting/supported someone living with/lived with a non-malignant progressive respiratory condition
3. Nurses working in primary care (practice) with patients with a non-malignant progressive respiratory condition

Participant type(s)
Mixed

Healthy volunteers allowed
No

Age group
Adult

Sex
All

Total final enrolment
31

Key exclusion criteria
Those unable to give understand the study and provide informed consent due to issues with capacity

Date of first enrolment
01/02/2014

Date of final enrolment
01/10/2015

Locations

Countries of recruitment
United Kingdom

England

Study participating centre

University of Hertfordshire
College Lane
Hatfield
United Kingdom
AL10 9AB

Sponsor information

Organisation
University of Hertfordshire

ROR
https://ror.org/0267vjk41

Funder(s)

Funder type
University/education

Funder Name
University of Hertfordshire

Alternative Name(s)
UH

Funding Body Type
Private sector organisation

Funding Body Subtype
Universities (academic only)

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study are not expected to be made available due to as this is a study that explores sensitive topics. However, within any published material an overview of the participant demographics will be included in relation to age, gender and the specified participant sub-group i.e. person with the condition, person supporting someone with the condition and nurse working in primary care

IPD sharing plan summary

Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
HRA research summary			28/06/2023	No	No
Participant information sheet	Family version 4	27/11/2013	09/06/2022	No	Yes
Participant information sheet	Patients version 4	27/11/2013	09/06/2022	No	Yes
Participant information sheet	Staff version 4	27/11/2013	09/06/2022	No	Yes
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes