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A qualitative exploration of the lived experience of chronic pain in individuals with a spinal cord injury

Submission date
20/03/2013

Recruitment status
No longer recruiting

Registration date
22/04/2013

Overall study status
Completed

Last Edited
20/03/2017

Condition category
Musculoskeletal Diseases

[X] Prospectively registered

[_] Protocol

[_] Statistical analysis plan

[X] Results

[_] Individual participant data

Plain English summary of protocol

Background and study aims
Interpretative Phenomenological Analysis (IPA) is a qualitative research method that aims to explore an individuals own lived experience of a phenomenon and has been successfully utilised in general chronic pain research. Pain is a significant side effect of spinal cord injury (SCI), particularly after discharge where patients do not have direct access to medicines, doctors or physiotherapy. IPA has not been used to study pain in these types of patients. This study is expected to last one year and aims to understand the experience of pain as a result of a spinal cord injury.

Who can participate?
Participants will be inpatients of at least 6 months and outpatients recruited from the National Spinal Injuries Centre, Stoke Mandeville Hospital (UK) database if they report suffering with chronic pain. They will have no other known chronic health condition that may affect their experience of pain. The lower age limit is 18 years, whilst there is no upper age limit. Both males and females are invited to take part.

What does the study involve?
All participants will have to give an informed written consent. Each participant will be interviewed either in a private room at the hospital or at their own home about their pain using a semi-structured format. This will include non-directive questions that allow the participant to take the lead and tell their own story. Interviews will be tape-recorded, transcribed and analysed using IPA in order to generate themes that are present in each account. These themes will then be further analysed and placed into broader (called superordinate) themes. Superordinate themes will be identified and described, presenting the most important aspects of a patients experience of pain. The deeper understanding of the lived experience of pain in SCI will suggest which aspects of the experience are most powerful in aiding or challenging integration into the community. It will also aid the development of SCI-specific pain management programmes.

What are the possible benefits and risks to taking part in this study?
No interventions will take place during this research, therefore there will be no risk of physical

harm to participants. Should participants wish to travel to have their interview, any expenses they incur will be reimbursed. It is possible, however, that talking about the experience of pain may distress some participants. However, part of IPA training involves being aware and monitoring the effect of the interview on the participant. If a participant does become distressed they may give as much or as little information to the interview as they want to. Participants will be allowed to have a friend or family member present during their interview. They will be allowed to halt the interview at any time. They may withdraw from the study and have their data destroyed should they so wish. As this is a qualitative study, quotes from participants will be used to demonstrate themes in the final report. All participants and anybody they may identify during their interviews will be given pseudonyms in order to protect their identity. Data will be stored in a password-protected computer database on the psychology department server at The University of Buckingham. All tapes will be kept in locked filing cabinets. Patient identifiers (demographic details) will be stored in the password-protected computer database, but separate from the corresponding data. Dr Katherine Finlay will be the custodian of this information and only those directly involved in the research will have access to this information.

Where is the study run from?
The study has been set up by The University of Buckingham, in collaboration with The National Spinal Injuries Centre, Stoke Mandeville Hospital, Aylesbury (UK).

When is the study starting and how long is it expected to run for?
May 2013 to August 2013

Who is funding the study?
The University of Buckingham (UK)

Who is the main contact?
1. Jasmine Hearn (0900611@buckingham.ac.uk)
2. Katherine Finlay (katherine.finlay@buckingham.ac.uk)

Contact information

Type(s)
Scientific

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers
N/A

Study information

Scientific Title
An interpretative phenomenological analysis of the experience of chronic pain in inpatients and outpatients with a spinal cord injury

Study objectives
So far, all of the research on pain in spinal cord injury has been quantitative. The experience of pain, however, is subjective, therefore this study is looking to explore the lived experience of chronic pain in individuals with a spinal cord injury using a qualitative methodology. This is expected to identify themes that suggest the most important aspects of an individual's pain experience. Themes that are prevalent across many individuals may help to develop pain management programmes specific to spinal cord injury.

Ethics approval required
Old ethics approval format

Ethics approval(s)
NRES Committee London - Bloomsbury, 14/05/2013, ref: 13/LO/0558

Study design
Single-centre observational study that will use a between-subjects qualitative design

Primary study design
Observational

Secondary study design
Cohort study

Study setting(s)
Hospital

Study type(s)
Other

Participant information sheet
Not available in web format, please use the contact details to request a patient information sheet

Health condition(s) or problem(s) studied
Spinal cord injury and pain, Musculoskeletal, Neuropathic Pain, General Healthcare

Interventions
Current interventions as of 28/08/2013:
For this research, all SCI patients who have been discharged from Stoke Mandeville Hospital within the last 20 years and inpatients of at least 6 months will be contacted. All will be aged 18 years or older. Of those who respond reporting chronic pain, between eight and twelve participants will be recruited. They will be asked to sign a consent form after reading the participant information sheet and an interview date and time will be arranged at the convenience of the participant. These interviews will be carried out in the participants own home or in a private room at Stoke Mandeville Hospital. Participants will take part in interviews lasting a maximum of 2 hours. A semi-structured format will be followed but the participant will take the lead on describing their experiences. The researcher will probe further into any topics raised by the participant that may be of interest to the research. Interviews will be tape-recorded, transcribed word for word and analysed using IPA. Transcripts will be read multiple times in order to gain familiarity before themes are identified among the text. These themes will be grouped into larger themes that suggest what the most important factors are in the experience of chronic pain after SCI.

Previous interventions:
For this research, all SCI patients who have been discharged from Stoke Mandeville Hospital within the last 20 years will be contacted. All will be aged 18 years or older. Of those who respond reporting chronic pain, between eight and twelve participants will be recruited. They will be asked to sign a consent form after reading the participant information sheet and an interview date and time will be arranged at the convenience of the participant. These interviews will be carried out in the participants own home or in a private room at Stoke Mandeville Hospital. Participants will take part in interviews lasting a maximum of 2 hours. A semi-structured format will be followed but the participant will take the lead on describing their experiences. The researcher will probe further into any topics raised by the participant that may be of interest to the research. Interviews will be tape-recorded, transcribed word for word and analysed using IPA. Transcripts will be read multiple times in order to gain familiarity before themes are identified among the text. These themes will be grouped into larger themes that suggest what the most important factors are in the experience of chronic pain after SCI.

Intervention Type
Other

Phase
Not Applicable

Primary outcome measure
Superordinate themes identified from transcripts that identify the key aspects of the pain experience in individuals with a spinal cord injury.

Interpretative Phenomenological Analysis will be used in order to find the outcome themes.

Secondary outcome measures
Subordinate themes will provide superordinate themes with detail and content.

Overall study start date

01/05/2013

Completion date
01/09/2014

Eligibility

Key inclusion criteria
The inclusion criteria were developed to be relevant to the research question, rather than to be representative of the population, as suggested by Willig, C. (2001). Introducing qualitative research in psychology: Adventures in theory and method. Buckingham: Open University Press.

Current inclusion criteria as of 23/08/2013:
1. Participants with a spinal cord injury must be inpatients of at least 6 months or outpatients of The National Spinal Injuries Center, Stoke Mandeville Hospital, Aylesbury
2. All participants both male and female must be over 18 years of age and sufferers of chronic pain for 6 months or longer. There is no upper age limit
3. Due to the fact that in depth interviews will be carried out, sufficient understanding of English must be held by all participants

Original inclusion criteria:
1. Participants with a spinal cord injury must be outpatients of The National Spinal Injuries Center, Stoke Mandeville Hospital, Aylesbury
2. All participants both male and female must be over 18 years of age and sufferers of chronic pain for 6 months or longer. There is no upper age limit
3. Due to the fact that in depth interviews will be carried out, sufficient understanding of English must be held by all participants

Participant type(s)
Patient

Age group
Adult

Lower age limit
18 Years

Sex
Both

Target number of participants
15

Key exclusion criteria
1. Participants with cognitive impairment or mental illness
2. Participants with articulation difficulties and an insufficient understanding of English
3. Any respondents with any other long term health condition that may affect the experience of pain, or be the cause of chronic pain (as opposed to the spinal injury)

Date of first enrolment

01/05/2013

Date of final enrolment
01/09/2014

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
The University of Buckingham
Buckingham
United Kingdom
MK18 1EG

Study participating centre
The National Spinal Injuries Centre
Stoke Mandeville Hospital
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Sponsor information

Organisation
University of Buckingham (UK)

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Sponsor type
University/education

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ROR
https://ror.org/03kd28f18

Funder(s)

Funder type
University/education

Funder Name
University of Buckingham

Alternative Name(s)

Funding Body Type
Private sector organisation

Funding Body Subtype
Universities (academic only)

Location
United Kingdom

Results and Publications

Publication and dissemination plan
Two papers have been published already, and a third is currently under review.

Intention to publish date
01/12/2017

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 the data being qualitative, and not having relevant consent.

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	results	01/07/2015		Yes	No
Results article	results	01/11/2016		Yes	No

HRA research summary	28/06/2023	No	No