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Patient and Public Involvement and Engagement in a PhD study - exploring self-harm in older adults

National Suicide Prevention Alliance Conference

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Overview

- Context to Patient and Public Involvement and Engagement (PPIE) in Health Research
- Setting up the PhD PPIE group
- Involvement of PPIE group throughout the research cycle of the PhD
- Strengths and Limitations of PPIE input
- Conclusions

Aims

- Critically reflect on the process and potential impact of involving robust PPIE in a doctoral study exploring self-harm and suicidal behaviour in older adults
- Identify challenges and opportunities of PPIE in research conducted with populations with lived experience on self-harm and suicide

What do ***we*** understand by Patient and Public Involvement and Engagement?

Context

What is Patient and Public Involvement and Engagement?

"Patient and public involvement entails research being carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. The word public can refer to patients, potential patients, carers and people who use health and social care services, people from organisations that represent people who use services as well as members of the public."

-NIHR, 2019

Context

1978 Alma Ata Declaration → 1997 NIHR INVOLVE UK → Last 2 decades: PPIE in Health Research

PPIE in Mental Health Research

WHY?

Mental Health Service Users Denouncement

Call for action:
1980s

Psychiatric Survivors and Feminist Movement

Context

- INVOLVE, funded and part of the National Institute for Health Research, established in 1996 to support active public involvement in NHS, public health and social care

- One of the few government-funded programmes of its kind in the world

- As a national advisory group, INVOLVE brings together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

www.invo.org.uk/

Context

- PPIE in mental health research can improve *acceptability and applicability of research*
  - Difficult to reach / under-served populations
  - Vulnerable populations

- In the UK, PPIE is a prerequisite for many funding bodies, but this can result in ‘tokenistic’ PPIE

Keele University Research User Group (RUG)

- Research User Group set up in 2006
- Over 130 members who have experiences of long-term conditions, or are caregivers or close relatives of someone with a long-term condition
- Members are working across over 60 research projects, which includes
  - Giving advice on research design
  - Reading and giving feedback on research materials (e.g. questionnaires, letters to patients, consents forms)
  - Commenting on research proposals
  - Membership of project steering committees
  - Co-applicants on grant submissions

Context

PhD Research Project: *Understanding self-harm behaviour in older adults*

PhD: Exploring Self-harm in older adults

- PPIE group from previous study on self-harm in primary care from Manchester and Keele identified need of studying self-harm in older adults (Carr et al., 2016)
- PhD project and studentship developed as a result **2016-2019**

Prof. Carolyn Chew-Graham

PhD student:
Isabela Troya

Dr Bernadette Bartlam

Dr Lisa Dikomitis

Dr Opeyemi Babatunde

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PhD Research Questions & Methods

- **Research Questions:**
  - What are the perceived motivations of self-harm?
  - What are the barriers and facilitators of access to care and support?
  - What are the potential roles, if any, of family, friends, 3rd sector support & primary care professionals, in supporting older adults who self-harm?
- **Methods:**
  - Systematic Review
  - Qualitative study: in-depth semi-structured interviews

PPIE group members for PhD

- Inclusion Criteria:
  - Previous self-harm lived-experience as an older adult (60 years or older)
  - Supporting or caring for an older adult with self-harm behaviour

- PPIE members from previous Manchester Keele study (Carr et al., 2016) were invited to take part in new PPIE group for PhD

- **Three** PPIE members were involved in the PhD throughout the 3-year study period

- Supported by Keele RUG

PPIE involvement in PhD

3 people contributed throughout the 3 year duration of the PhD

6 workshops/meetings held with PPIE members and researcher(s)

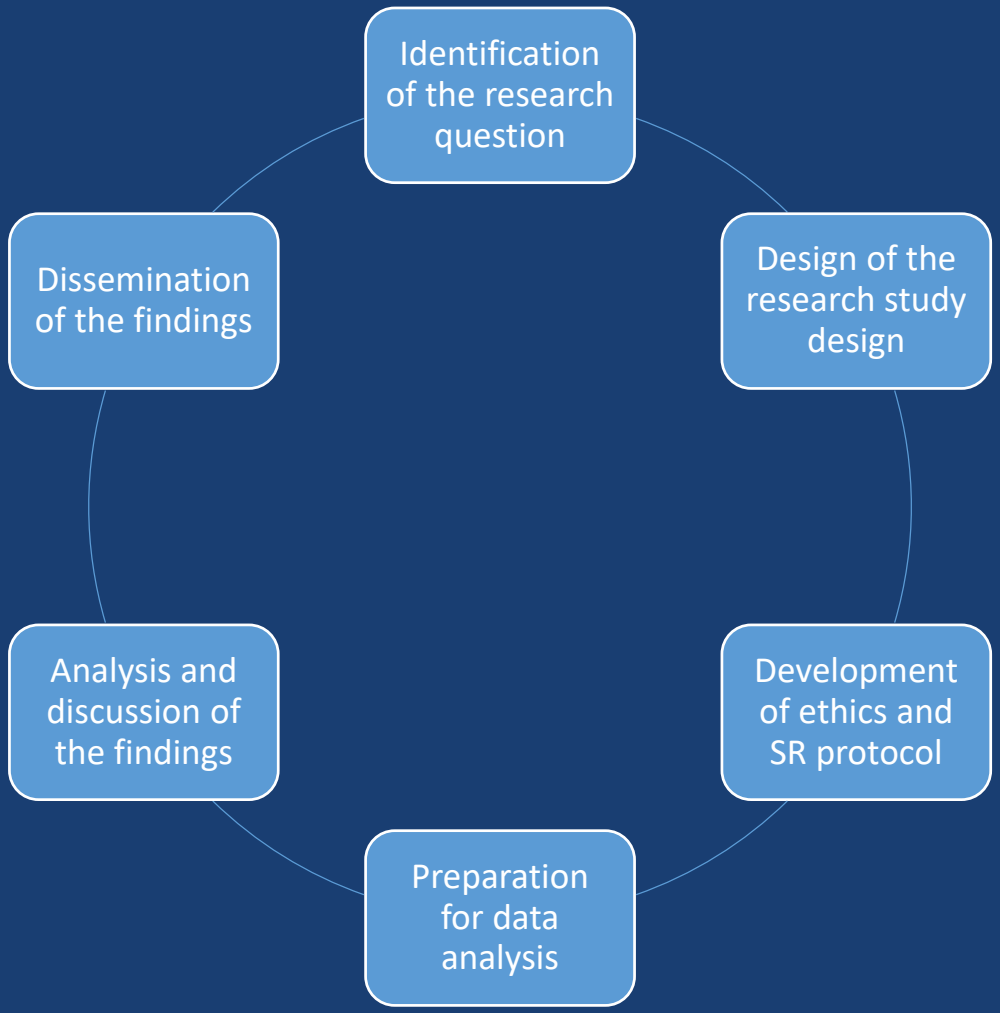
Ongoing communication and updates (email and mail correspondence) between PPIE members and researcher(s)

Level of involvement in research discussed amongst PPIE members and research team

Full documentation of discussion and changes made as result of PPIE input

Pre-PhD 2015	• PPIE group from self-harm in primary care (Carr et al., 2016) identified need of research in self-harm older adults
Jan. 2017	• First PPIE meeting for PhD. Research questions agreed and discussed. Review of public facing documentation.
June 2017	• Introduction of systematic review concept and review of outline proposal. Identification of avenues for recruitment.
Sept. 2017	• Review of preliminary results of systematic review. Identifying dissemination avenues for systematic review.
March 2018	• Review of preliminary results of qualitative interviews. Discussion of analysis.
April 2019	• Identification of avenues of dissemination. Ideas for future studies discussed
October 2019	• Review of animated video summarising PhD findings

PPIE in the PhD throughout the research cycle



PPIE Meeting 1

PPIE meeting 1 19.01.2017

1. Research aim & questions
2. Definition of self-harm
3. How to focus data collection & study design
4. Review of participant facing documents for Ethics Application

Terminology used

Self-harm

Self-poisoning

Cutting

Self-injury

Suicidal behaviour

Deliberate self-harm

Parasuicide

PhD Research Questions

Before & After

1. What are the reasons behind self-harm in some older adults?

2. What are the barriers and facilitators of access to care and support?

3. What role do family, health services, and support groups have in supporting older adults who self-harm?

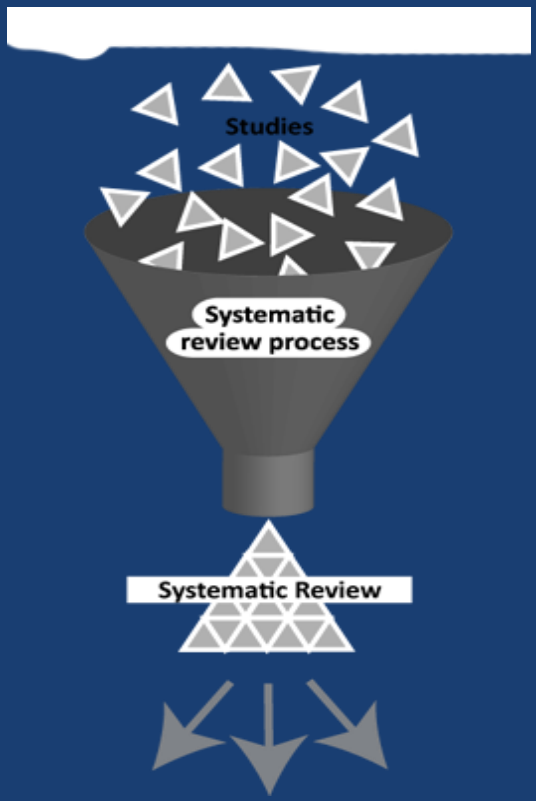
1. What are the **perceived motivations** of self-harm?

2. What are the barriers and facilitators of access to care and support?

3. What are the **potential roles, if any,** of family, friends, 3rd sector support & primary care professionals, in supporting older adults who self-harm?

PhD Study Design

- Systematic Review
- Qualitative Study



PhD – Qualitative study

Before & After

Semi-structured interviews:

-people aged **40+**

-**GPs**

(approx. 8-10 in each group)

Recruitment:

-self-harm support groups

-advertising in local community

-GP practices

-social media

Semi-structured interviews:

-2 interviews with people aged **60+**

-1 interview with **3rd sector workers**

(approx. 8-10 in each group)

Recruitment:

-support groups: **self-harm & age**

-advertising in local community

-social media

PPIE Meeting 2

PPIE meeting 2 27.06.2017

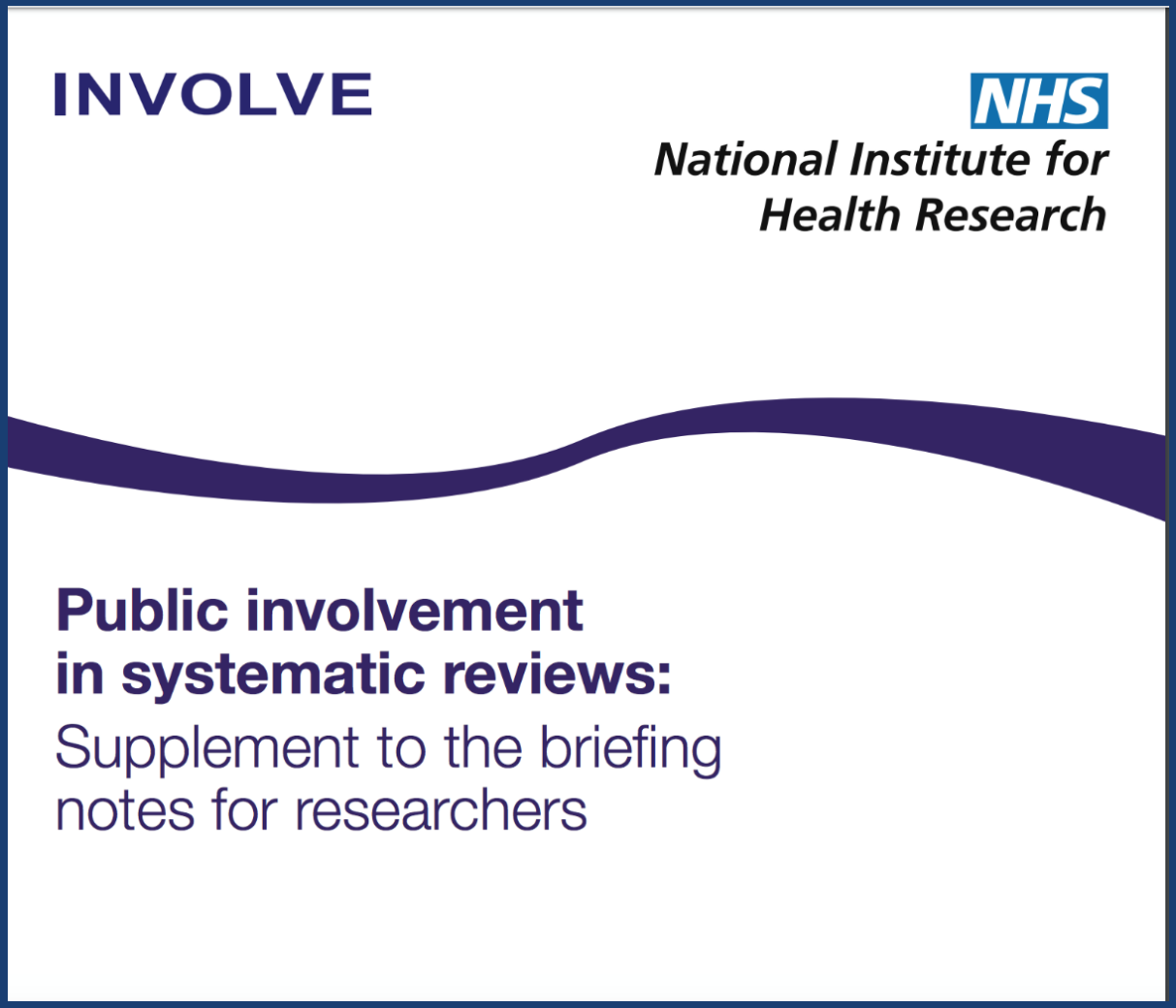
1. Qualitative study
   - Recruitment of participants
2. Systematic Review
   - Concept introduced
   - Systematic Review self-harm older adults
   - Inclusion and Exclusion criteria

Would you include PPIE input in a Systematic Review?

How would you include PPIE in a Systematic Review?

Systematic Review

- Defined SRs and their importance
- Use of INVOLVE resources for SRs
- Review the characteristics of self-harm in older adults (60 years or older)
  - Risk factors (bereavement, marital status, etc)
  - Methods (injury, poison, etc)
  - Rates (%)
- Search strategy for SR and terms to be included discussed



https://www.invo.org.uk/posttypepublication/public-involvement-in-systematic-reviews/

PPIE Meeting 3

PPIE meeting 3 26.09.2017

1. Systematic review of self-harm in older adults
   - Preliminary findings discussed
   - Ideas for dissemination
2. Qualitative study
   - Potential / anticipated problems when interviewing participants discussed
   - Preparation for data analysis

How would you include PPIE in the analysis of qualitative data?

Qualitative study

- Recruitment commenced and slow participation rate
- PPIE members suggested attending the local self-harm support group regularly, as they felt this would make potential participants feel more comfortable
- As a result increased participation
- Preparation for data analysis of qualitative data for next workshop

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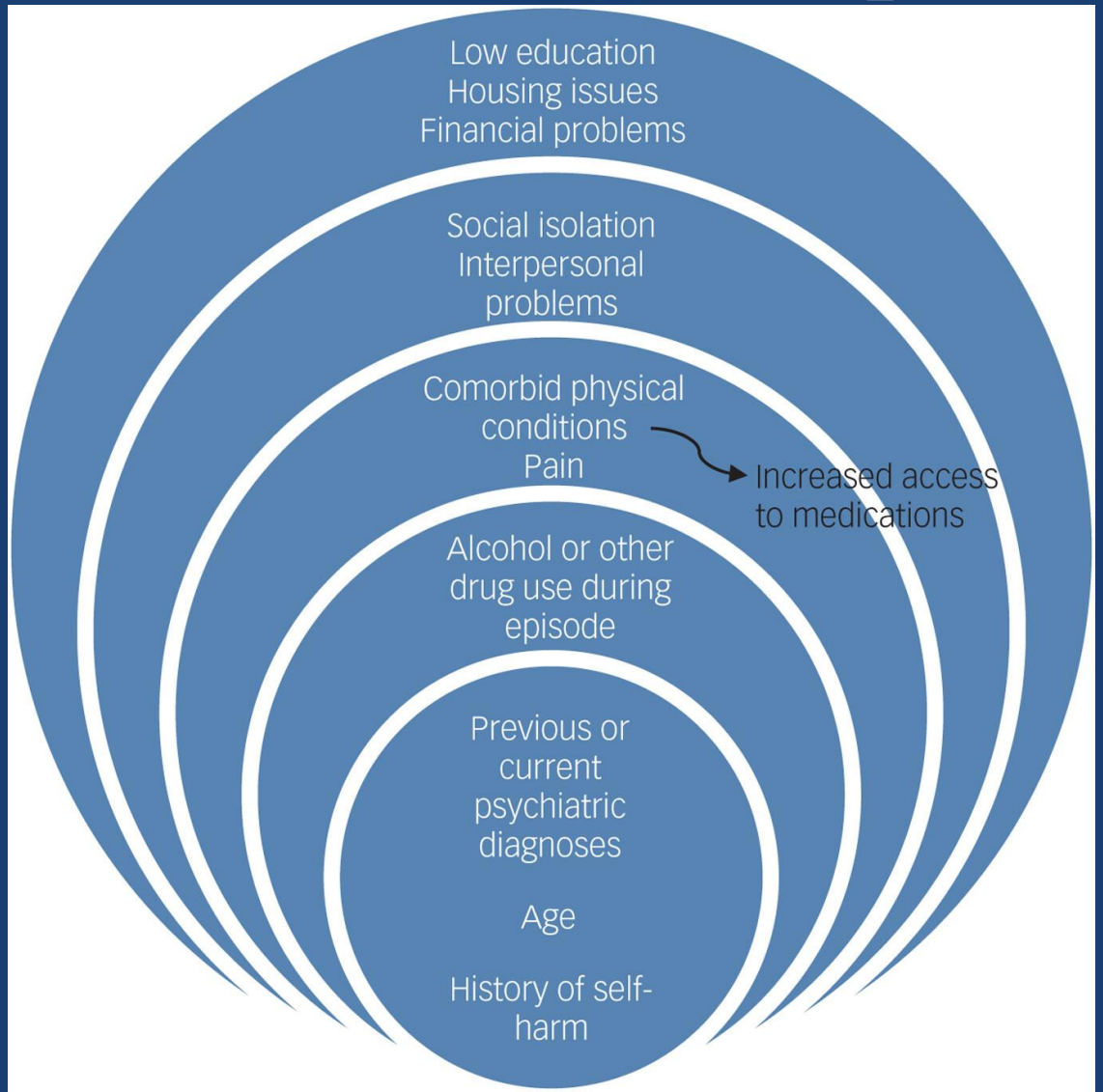
Diagrammatic conceptualisation of SR findings



From Troya et al., 2019a, BJPsych

PPIE Meeting 4

PPIE meeting 4 20.03.2018

1. Systematic Review
   - Strategies to disseminate findings of systematic review
   - Pathways for engagement: Information leaflet
2. Qualitative study
   - Analysis and interpretation of findings

How do you think PPIE can contribute to dissemination activities?

SUMMARISING WHAT WE KNOW

- Self-harm in older adults is a concern.
- There is increased risk of self-harm repetition and suicide in older people.
- Other health related problems are frequent in older adults, and therefore increased access to means (e.g. medication).
- Social isolation, previous mental health problems, financial problems, alcohol and drug use increases risk of self-harm in older adults.
- Older adults visit their GP more frequently, giving an opportunity of detection, access to support and possible prevention.

GETTING HELP

HELPLINES

Samaritans
(Open 24/7)
116 123

Silver Line
(Helpline for older people)
0800 470 8090

Age UK
(Helpline for older people)
0800 055 6112

ONLINE

Mind
(National Organisation)
mind.org.uk

National Self-harm network
(Online forum)
nshn.co.uk

Harmless
(National Organisation)
harmless.org.uk

YOUR GP

Your local GP will be able to provide advice and support.

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SELF-HARM IN OLDER ADULTS

This leaflet aims to give information to people affected by self-harm.

The Keele difference

Developed by I. Troya
(PhD student at Keele University)
in collaboration with the study's Patient and Public Involvement and Engagement Group

INTRODUCTION

Self-harm can affect anyone regardless of age but most of the research on self-harm is about younger people.

WHAT IS SELF-HARM?

There are different definitions as well as words used to describe self-harm.

In the UK, the definition which is mostly used is the one provided by NICE (National Institute of Health and Care Excellence):

"any act of self-poisoning or self-injury carried out by a person irrespective of motivation".*

Other words used to describe self-harm:

- Self-injury
- Overdose
- Cutting

Others define self-harm as a coping mechanism that is harmful to a person's well-being.

*NICE (2012). Self-Harm: longer term management. London: NICE

COMMON SELF-HARM METHODS

People self-harm in different ways, but common methods are cutting, burning, overdosing, and hitting one self. In older people, overdose of tablets, often in the context of alcohol use, is common.

WHY IS SELF-HARM IMPORTANT IN OLDER ADULTS?

Despite not being as common as in younger people, self-harm is a concern amongst older adults as self-harm is a risk factor for suicide, and suicide rates are amongst the highest in older men. Self-harm can be hidden – and is not always recognized as a problem by the person or others.

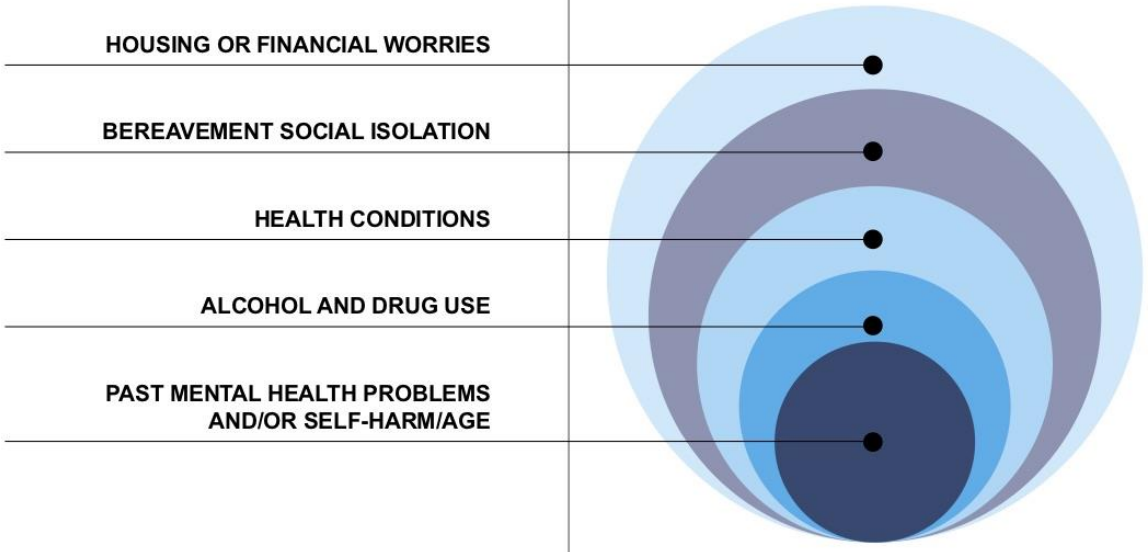
WHAT MAKES OLDER ADULTS SELF-HARM?

Not every older adult who harms him or herself does so with the wish to end their life. Other reasons may be to seek help, gain relief from emotional pain, escape a situation they feel is intolerable, amongst others.

WHO IS MOST AT RISK?

Research suggests that older people with mental health, physical, social, and personal problems are at increased risk of self-harm.

RISK FACTORS FOR SELF-HARM IN OLDER ADULTS



BJPsych | The British Journal of Psychiatry (2019)
Page 1 of 15. doi: 10.1192/bjp.2019.11

Review

Self-harm in older adults: systematic review

M. Isabela Troya, Opeyemi Babatunde, Kay Polidano, Bernadette Bartlam, Erin McCloskey, Lisa Dikomitis and Carolyn A. Chew-Graham

Background

Self-harm is a major public health concern. Increasing ageing populations and high risk of suicide in later life highlight the importance of identification of the particular characteristics of self-harm in older adults.

Aim

To systematically review characteristics of self-harm in older adults.

Methods

A comprehensive search for primary studies on self-harm in older adults was conducted in e-databases (AgeLine, CINAHL, PsycINFO, MEDLINE, Web of Science) from their inception to February 2018. Using predefined criteria, articles were independently screened and assessed for methodological quality. Data were synthesised following a narrative approach. A patient advisory group advised on the design, conduct and interpretation of findings.

Results

A total of 40 articles ($n = 62\,755$ older adults) were included. Yearly self-harm rates were 19 to 65 per 100 000 people. Self-poisoning was the most commonly reported method. Comorbid physical problems were common. Increased risk repetition was reported among older adults with self-harm history and previous and current psychiatric treatment. Loss of control, increased loneliness and perceived burdensome ageing were reported self-harm motivations.

Conclusions

Self-harm in older adults has distinct characteristics that should be explored to improve management and care. Although risk of further self-harm and suicide is high in all age cohorts, risk of suicide is higher in older adults. Given the frequent contact with health services, an opportunity exists for detection and prevention of self-harm and suicide in this population. These results are limited to research in hospital-based settings and community-based studies are needed to fully understand self-harm among older adults.

Declaration of interest

None.

Keywords

Self-harm; suicide; systematic review.

APR 1 2019

Self-harm in older adults: a forgotten group?

No Responses »

Posted by Karen Birnie, Haridha Pandian>, Derek Tracy

Self-harm, the *"act of self-poisoning or self-injury... irrespective of motivation"*, is an enormous clinical and public health concern, which can have a devastating impact on the individual, family members, friends and broader society. We too commonly perceive self-harm as an issue affecting young people (Townsend, 2014) and the literature has largely focussed on this age-group. However, rates of suicide are actually among the highest in the elderly (World Health Organization, 2014), and self-harm is a major risk factor for suicide completion.

What separates self-harm in younger people to that seen in older adults? Surprisingly, there has been little robust literature published in the last decade exploring this and the silence is deafening. This gap is amplified when we consider the UK's ageing population: in mid-2017, 18.2% of the population was aged 60 years or older, and this is projected to rise to 20.7% by 2027 (Office for National Statistics, 2018). It is critical to consider the particular nature of self-harm in older adults to inform clinical practice and management, including suicide prevention.

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Opinion
Mental health

Mental health problems don't end with age. Older people need help too

Emily Reynolds

@rey_z
Tue 9 Apr 2019 08.00 BST

Loneliness is sometimes presented as the main reason for older people's mental ill-health, but that's not the case

After years languishing in the dark, mental illness is finally getting its moment in the spotlight. Frustrating political football it may be, but one thing can't be denied - it's making headlines more than ever. Focus, largely, has been on young people - crises in child and adolescent mental healthcare and in student populations have been both persistent and significant. But mental illness doesn't end with reaching adulthood - often, in fact, it doesn't end at all.

New research from the British Journal of Psychiatry into self-harm in older people puts this into stark perspective. A meta-analysis of 40 studies found that yearly self-harm rates were about 65 per 100,000 people, with risk of repetition and of suicide also higher than average. Self-harm is still seen as a problem among younger demographics; and while that remains true, this data proves that the issue is even more complex and diffuse than we thought.

The findings are not wholly surprising. In 2014, the World Health Organization found that suicide rates were highest in people aged over 70 in almost all regions of the world. The Royal College of Psychiatrists (RCP) also found that 40% of older people in GP clinics experience mental ill-health; this rose to 50% in general hospitals and 60% in care homes. And, as the Mental Health Foundation points out, the UK population is ageing rapidly - since 1974, the number of older people in the UK has grown by 47%. By 2027, the Office for National Statistics predicts, 20.7% of the UK population will be aged 65 or over, compared with 15.9% in 2007. The problem, clearly, is not going away.

Combating loneliness is often seen as the key here - just this year, £11.5m was awarded to organisations designed to deal with the issue. But it isn't enough. Loneliness is sometimes presented as the primary problem when it comes to tackling mental ill-health in older people - and, while it indubitably contributes, this explanation doesn't really go far enough. Many of those experiencing self-harm, suicidal thoughts or other signs of mental distress already have diagnoses - they're people who have dealt with mental illness their whole lives. Social isolation may contribute to their problems, yes, but it's not the full picture.

PPIE Meeting 5

PPIE meeting 5 09.04.2019

1. Overview of PhD findings
2. Strategies to disseminate findings
3. Pathways for engagement: video script

Understanding self-harm in older adults

Isabela Troya, PhD student

A PhD research project exploring self-harm in older adults

How?

Individual interviews with 2 participant groups: a) Older adults engaging in self-harm; b) Support workers with experience supporting older people who self-harm. Older adult participants offered a follow-up interview. Ethical approval was obtained from Keele University's Ethics Review Panel.

When?

Interviews conducted from September 2017 to September 2018 across different localities in England.

Why?

Self-harm is a public health concern. Despite its impact, there is not much research exploring self-harm in older adults. Specifically, no research looking into why older adults self-harm and they use to seek care for their self-harm has been conducted

Patient Advisory group

A patient advisory group conformed by older adults with self-harm history, carers, and support workers, was involved in designing the study and analysing findings. Involvement of this group ensured the research had lived-experience perspectives.

Conclusions

+ Self-harm is often concealed due to feelings of shame. Self-harm occurred along a spectrum of no-suicidal intent to high-levels of intent, suggesting self-harm holds different functions.

+ Despite frequent contact with health services, it was difficult to talk about self-harm. As well, when help was sought from health services, these were viewed as superficial in the case of primary care and constrained in the case of secondary care.

+ Third sector groups offer support to older adults who self-harm, but this was limited: groups are not available in every locality and may be commissioned on a short-term basis.

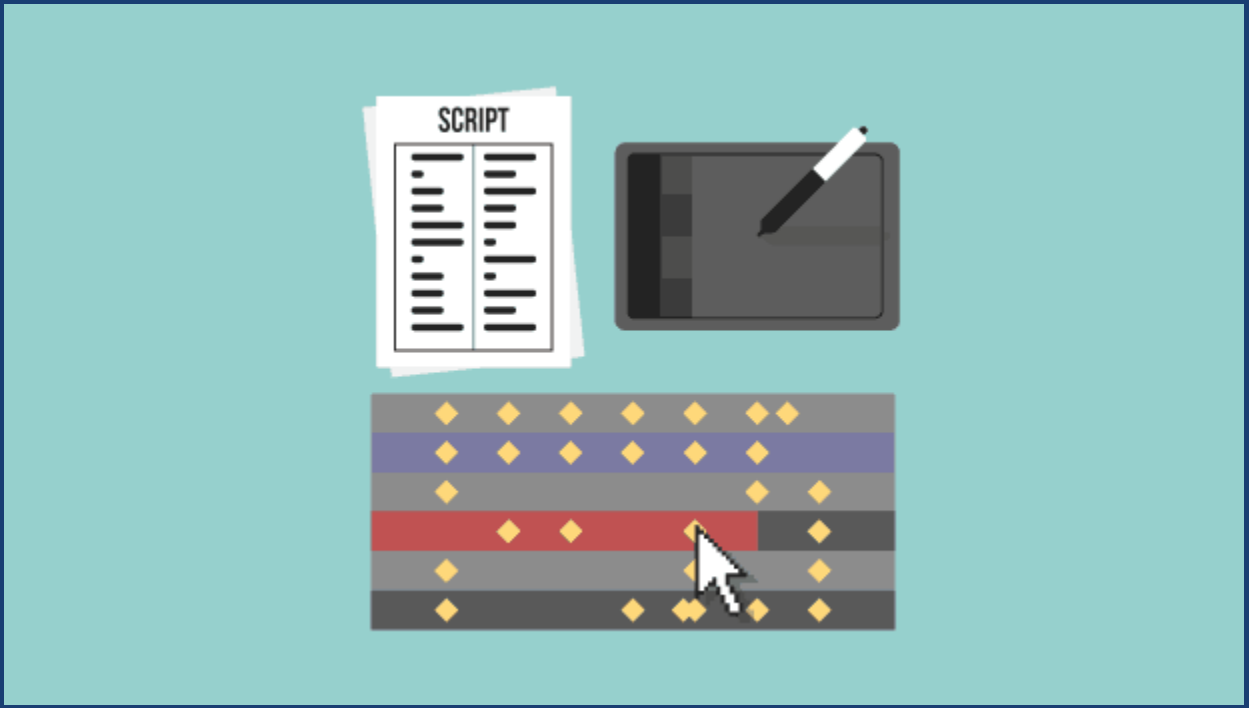
Findings

24 interviews conducted with 16 participants. All older adults had diagnoses of mental illness in addition to physical illness.

+ Participants identified various stressors: adverse events, loss, interpersonal and health problems, which led them to self-harm. A sense of shame and stigma amongst older people using self-harm to manage distress was also reported.

+ Participants described the first decision of seeking help for self-harm as difficult. Persistent & repeated requests were needed before help was found, with older people finding it difficult to access support.

Video Script Animated Video



PPIE Meeting 6

PPIE meeting 6 31.10.2019

1. Development of animated video
   - Graphics
   - Narrative

Insert video

Implications

- Epistemological perspective: public's role beyond informants
  - Co-construction of knowledge
- Conceptualisation of study: public's perspective as a critical component
- Add to literature of self-harm in older adults
- Document and identify possible opportunities for others to consider when researching sensitive topics and/or vulnerable populations

What challenges and opportunities do you see with involving PPIE in research?

Benefits of PPIE in PhD study

- PPIE contributed to improving relevance, legitimacy and validity of findings of PhD study
- Added perspective and understanding of study findings, as well as ensuring a broader capture and prioritisation of the public's needs
- When conducted with adequate support and guidance, PPIE can offer researchers, patients and the public continuity in the research process
- Continuous PPIE involvement was achieved through careful consideration of the PPIE group's capacity, level of involvement, respect of wellbeing and adequate training and support

Challenges of PPIE in PhD study

- Ensuring continuous involvement and continuity throughout the research process
- Representativeness/diversity of PPIE group
- Relatively ‘small’ PPIE group
- Avoiding tokenistic involvement: the level of PPIE involvement was carefully considered and discussed amongst the research team, PPIE coordinator and PPIE members
- Overburdening PPIE members was a concern when thinking of the level of involvement in this sensitive topic. Through discussions, a balance was reached to ensure meaningful involvement whilst maintaining PPIE members’ wellbeing

TABLE 1 Challenges and suggestions when involving PPIE in a doctoral research project

Challenges[3,19,20]	Implications of unresolved challenges	Strategies used	Suggestions for encountered challenges	Considerations and suggestions when involving at risk populations
Time-related pressures	Superficial involvement resulting in lack of meaningful impact	Liaised with the Institute's established PPIE network 8 months prior to the first meeting, contact with PPIE coordinator was made in order to have sufficient time for involving patients and logistic of PPIE involvement	Consideration of PPIE involvement from early stages of planning research (ideally when preparing funding application) Allocate time for possible delays; realistic deadlines Liaise with PPIE network and have lead PPIE coordinator	Defining clear roles and responsibilities Prioritising PPIE's well-being Offering adequate support and training Acknowledging contributions Promoting PPIE throughout the research cycle Offering accessible and inclusive approaches tailored for the specific PPIE members
Resources (time and funding)	Potential burden caused to PPIE members Superficial involvement due to insufficient time and financial consideration	Secured separate funding for PPIE activities, including engagement Liaised with PPIE coordinator for reimbursement of members' involvement Researcher allocated time for PPIE activities	Early consideration of PPIE involvement in order to plan and allocate enough time and funding Liaise with PPIE network Use available resources for guidance and templates of PPIE[1] Offer reimbursement to PPIE members Allocate enough time for PPIE involvement	
Avoiding tokenistic involvement	Lack of meaningful impact and PPIE 'tick box' approach used for funding applications resulting in superficial involvement No careful consideration of involvement of PPIE's time and potential contribution	PPIE workshops planned in multiple times of the research project After each workshop, detailed account of impact of PPIE documented and shared with research team and PPIE members Sufficient time and space given to PPIE group to allow for in-depth discussion	Keep clear and accessible records of PPIE involvement throughout the different stages of the research project Clarify involvement and level of involvement by each of the members Value the involvement, contribution, added perspective given by PPIE Liaise with research team and PPIE coordinator to ensure meaningful involvement	
Continuity	Discontinued involvement resulting in superficial PPIE Disregard of PPIE's potential contribution and time	PPIE workshops and objectives planned in advance and discussed with PPIE group and coordinator Feedback PPIE members regarding stage of research Encourage participation through thoughtful consideration of PPIE needs and capacity of involvement	Provide clear expectations, define roles and responsibilities, involvement timelines Ensure PPIE's needs are considered and involvement is not resulting in burdening members Ensure feedback is provided regarding PPIE's impact and contribution to the study, as well as stage of study Acknowledge the different needs PPIE members may have which can limit their ongoing involvement	

Key Considerations for PPIE

Time pressures

Resources: time & funding

Level of Involvement

Support

Recognition

Working sensitively

Clear & open communication

Continuity

Summary

- This PhD was developed during discussion at a PPIE meeting from a previous study
- We ensured PPIE involvement throughout the entire research process
  - Systematic review
  - Qualitative study
  - Dissemination activities and outputs
- Further research ideas generated

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Thank you for your attention
Any questions?

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Acknowledgements

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