

What are the impacts of social media?

A qualitative study exploring the experiences of posting about dementia online

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BACKGROUND

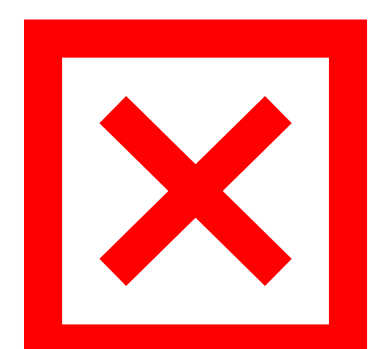
Social media is increasingly used by people living with dementia (PLWD) and their care partners to seek information, advice, resources, and support.

This engagement is often accompanied by **disclosure of a dementia diagnosis or identification as a care partner**.



Benefits of self-disclosure:

Facilitating peer interactions
Helpful for isolation
Social support



Risks of self-disclosure:

Exposure to misinformation
Social repercussions
Stigma

Given the benefits and risks, the consequences of this disclosure remain unclear.

OBJECTIVES

Current study aim

Deepen our understanding about the motivations and impacts of self-disclosing a personal dementia diagnosis or identifying as a care partner on social media.

Project goal

Develop an evidence-based resource to support decision-making around social media use in dementia.

METHODS



Semi-structured interviews (n = 19 to date)

Questions focused on:

- 1) Social media activity
- 2) Self-disclosure and feelings of support
- 3) Access to resources about social media use



Interview recordings were transcribed



Coding using constant comparative analysis

Preliminary coding guide developed

Two coders applied coding guide to 1 transcript

Coding discrepancies discussed and resolved

Coding guide iteratively refined



Final overall unweighted kappa of >0.8
before remaining transcripts were coded independently.

PRELIMINARY RESULTS

“

I think social media is powerful because it [...] gives you a voice

”

16

Care partners

3

PLWD

Types of posts



Advice seeking

Sharing personal stories

Motivations for posting



Raising awareness

Documenting life

Feelings before posting



Nervousness
Hopefulness

Feelings after posting



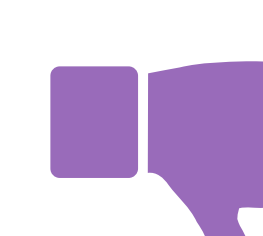
Nervousness
Validation
Relief

Helpful responses



Providing advice and support

Unhelpful responses



Oversharing and negativity

NEXT STEPS

Co-creation workshops to develop resources supporting those wishing to disclose about their dementia experiences or respond dementia posts on social media [ongoing, n = 1 completed]