Knowledge and information needs of unpaid caregivers of individuals with a current or past pressure injury: A qualitative research study

"I personally prefer digital [media], if

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appreciated." (CG2)

heal." (CG8)

ulcers." (CG1)

"We tell him to, how to lie on

his side, instead of lying on his

back, and try to shift, try to tell

him to not sit so often.....And

try to avoid constant pressure

on that particular spot to let it

"I'm aware infection is a big

"I never had to put a bandage

on like this before, but that's

not a big deal. I've watched

them often enough to know

what to do." (CG11)

issue with people having

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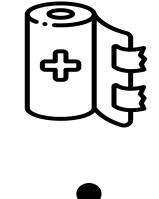




BACKGROUND

1 in 3 individuals living with SCI have a PI¹

Pressure injuries (PIs) are localised damage to the skin resulting from prolonged tissue deformation²



PIs reduce the quality of life among affected individuals and their caregivers³



Unpaid caregivers play a vital role in preventing and managing PIs but may lack the knowledge and training needed to provide proper care for Pls

There is a lack of research exploring the educational needs that unpaid caregivers require to help prevent and manage PIs

OBJECTIVE

To explore the existing knowledge and information needs of unpaid caregivers assisting individuals with a current or past PI.

METHODS

Study Design: Qualitative descriptive study using semistructured interviews

Inclusion Criteria:

- Unpaid caregiver providing care for a person living with a current or past history of a PI
- At least 18 years of age
- Speak and understand English

Interviews were transcribed verbatim, reviewed for accuracy, and coded using NVivo. Inductive content analysis was used to generate themes and subthemes.

PARTICIPANT DEMOGRAPHICS

Eleven unpaid caregivers (n=3 male, n=8 female) participated in this study



All caregivers were providing unpaid care for a relative



Most caregivers were assisting relatives who lived in the same household (n=9)



All caregivers had some form of postsecondary school education

Caregivers provided care ranging from less than 1 year to more than 10 years (median 24 months)

RESULTS

Three themes and seven subthemes were generated

there's some kind of a link or somewhere where you can search and specifically write questions to "The wound nurses were narrow your search... I find that's the fabulous in sharing most helpful for myself." (CG9) information. They also trained me and watched me do dressing changes so that they signed off on me taking supplies outside and doing them outside which I really

Caregivers'

existing

knowledge

"I wish I knew the symptoms of

these pressure ulcers, so I guess I

tried to manage before it led into

open sores." (CG6)

know them now, before now I wish

I knew the symptoms, I would have

"Dr. Google is my best friend and worst enemy....Cause the internet's also full of garbage." (CG2)

"I can find a couple of things, but I don't really like to trust the internet too much." (CG7)

Preferred source of information of delivery information

Knowledge Acquisition: Source and Preferred **Method of Information**

Delivery *(3) Knowledge about

Pressure Injuries

delivery

Timing of information

"Well obviously before it happened so that

Receiving

information

during Pls

"I think a pamphlet might be

because [PIs] can be very

that I should [do]..." (CG4)

they suggest." (CG9)

helpful just to always have on hand

"I look at some of the pictures that

common...So just to have that on

hand about the necessary steps

are there and compare it to my

own situation and see what looks

similar enough and then read the

information that's there and what

"Probably during [the PI]

world that I would look

because there's no way in the

something up like that, because

I would have no interest." (CG3)

you don't have to deal with it to begin with. That information would be helpful because I didn't realize how quickly they can present themselves and how quickly they can go from bad to worse. So having that information or details in terms of what to lookout for or [how] to help your situation would be helpful overall." (CG9)

DISCUSSION

- **Caregivers had a basic understanding of PI prevention and management, but lacked specific knowledge about PIs, a** finding consistent with previous research⁴
- Consistent with previous research,⁵ caregivers identified healthcare professionals as the most trusted source of information
- **Paradox of the Internet as the most preferred but least trustworthy source of information** was consistent with previous research related to other healthcare conditions^{5,6}
- **Pamphlets, videos, and pictures were perceived to be useful educational tools, a finding supported by studies related** to PIs and other medical conditions^{7,8}
- There is no consensus among participants regarding the ideal time to receive PI information, whether prior to a PI or at the time of PI diagnosis similar to existing literature^{9,10}
- The content and timing of information should be tailored to the caregivers' needs and situation, a finding noted by previous research^{11,12}

IMPLICATIONS & RECOMMENDATIONS

Findings from this work may inform the development of effective PI educational tools related to PI prevention and management

For information to be helpful, the content and timing of delivery must be tailored to the caregiver's situation and characteristics of the caregiver

Healthcare professionals should direct patients and caregivers to reliable internet sources during medical visits or be more involved in the development of reliable online resources

CONCLUSION



Caregivers desire more reliable online PI resources



Pamphlets, videos and pictures may help caregivers better understand PIs



PI content and timing of delivery should be tailored to caregivers' needs and situation



Healthcare professionals should be involved in designing and/or curating high-quality PI instructional resources

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