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Self-management for Persons with Limb Osseointegration

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Background

- Osseointegration (OI) is a surgical procedure that allows for a prosthesis to be connected to a metal implant that is inserted in the bone of the residual limb.
- In Canada, OI is a relatively newer option available for those living with limb loss. Persons usually return home, after care in a larger centre, to communities with very few health professionals who are knowledgeable about OI.
- Complications may arise post-OI, such as infection, which cause individuals to seek strategies for their self-care.
- Accessing health information through various online sources and platforms, such as social media, is common but how one determines the trustworthiness and reliability of the discovered health information and decides to add a strategy to their self-management plan is not well understood.

Aim Statement

- The aim of this study was to understand how individuals living with limb OI make decisions about their self-management including where they seek information from, how they use it and how they decide that information is valid.

Methodology

- A constructivist grounded theory approach was used for the study to facilitate the construction of a theory grounded in interviews with persons with OI.
- Grounded theory is the most appropriate methodology for research questions about process, such as the process of finding, using, and evaluating health information.
- The research study received approval from the Trent University Research Ethics Board (file 28340).

Sample

Participants were recruited from Facebook forums for people with OI as well as by word of mouth. Inclusion criteria included:

  - Person living with OI at any level or of any limb and for any amount of time
  - Ability to speak and understand English
  - 18 years or older and able to provide informed consent

Data Collection

Individual, online interviews that lasted between 60 – 90 minutes. Participants were asked the following questions.

What does managing your OI look like for you?
What do you do if you have a question about managing your OI?
Who is important in your community to support your self-management of your OI?
How do you seek health information related to your amputation and osteointegration?
How do you decide to use the information that you have found?
How do you evaluate whether information you have used contributes to your health?

Findings

Ten persons with limb OI participated in the study, six females and four males.

- Average age of participants was 55.5 years ranging from 34 to 65 years of age.
- Educational attainment ranged from university (30%) to college (40%), and high school completion (30%).
- Half of the participants were from Canada, three from the United States, and two from Australia. Four lived in large urban areas (>100,000 population), three in smaller urban areas (30-100,000 population) and the remaining three lived in rural areas (<30,000 population).
- Employment: five of the participants worked either full-time or part-time, and the other five were retired or unemployed.

The **five phases of information sharing** are captured in the table along with participant quotes.

Phase	Example of related Participant Quote
Seeking Information	*"I do go to journals...I belong to probably about six different Facebook groups and a couple of blogs that I look out."* (P9)
Deciding what information to use and try	*"If it's something that I have not heard before, then I will usually reach out to another person who's had osseointegration and say, 'Hey, have you heard of this?' I will try to bounce it off a few different people just to see if it's valid or worth trying for me."* (P2) *"there is a lot of emotion in OI because people are very emotional about it, I tend to discount what they say because their decisions are coming from emotion and not from facts or data or experience."* (P8)
Trying things out	*"I have nothing to lose so I am willing to try it, especially if it is natural and it is not invasive"* (P1) *"I mean it couldn't be any worse than an infection every six months, so I just tried it out and it worked"* (P10)
Validating the information	*"trial and error"* (P5) *"I tested to see if I could sleep in it, I slept and I didn't wake up, I didn't find it uncomfortable. My hips weren't bothering me when I woke up in the morning"* (P6). *"try and fails…it's not that I have asked question it's more that I have read people who has asked question and had responses."* (P7)
Sharing information with peers	*"I rely on them as well and we talk in between ourselves about which is the best way to deal with [the situation]...we tend to talk in between ourselves because no one else really understands, your general doctor doesn't understand..."* (P3) *"I've had a couple of three people reach out to me and ask me questions about it [having OI]. So, I have given my input on their decision-making you might say"* (P4).

The participants described times in their journey that self-management decisions were made; these occurred at each of **four stages in their OI journey**.

1) The decision to have OI
2) The decisions of self-care in the initial phases or steps
3) Dealing with challenges such as infection or pain
4) Moving into a routine, or the day-to-day care

Phases of Information Sharing & Recommendations

At each of these steps in their journey participants undertook a process of decision making, related to their self-management of living with OI (Figure 1). While not all participants described each phase (or step) of the process, nor was there a clearly linear path between phases, aspects of each phase or step were discovered in each interview.

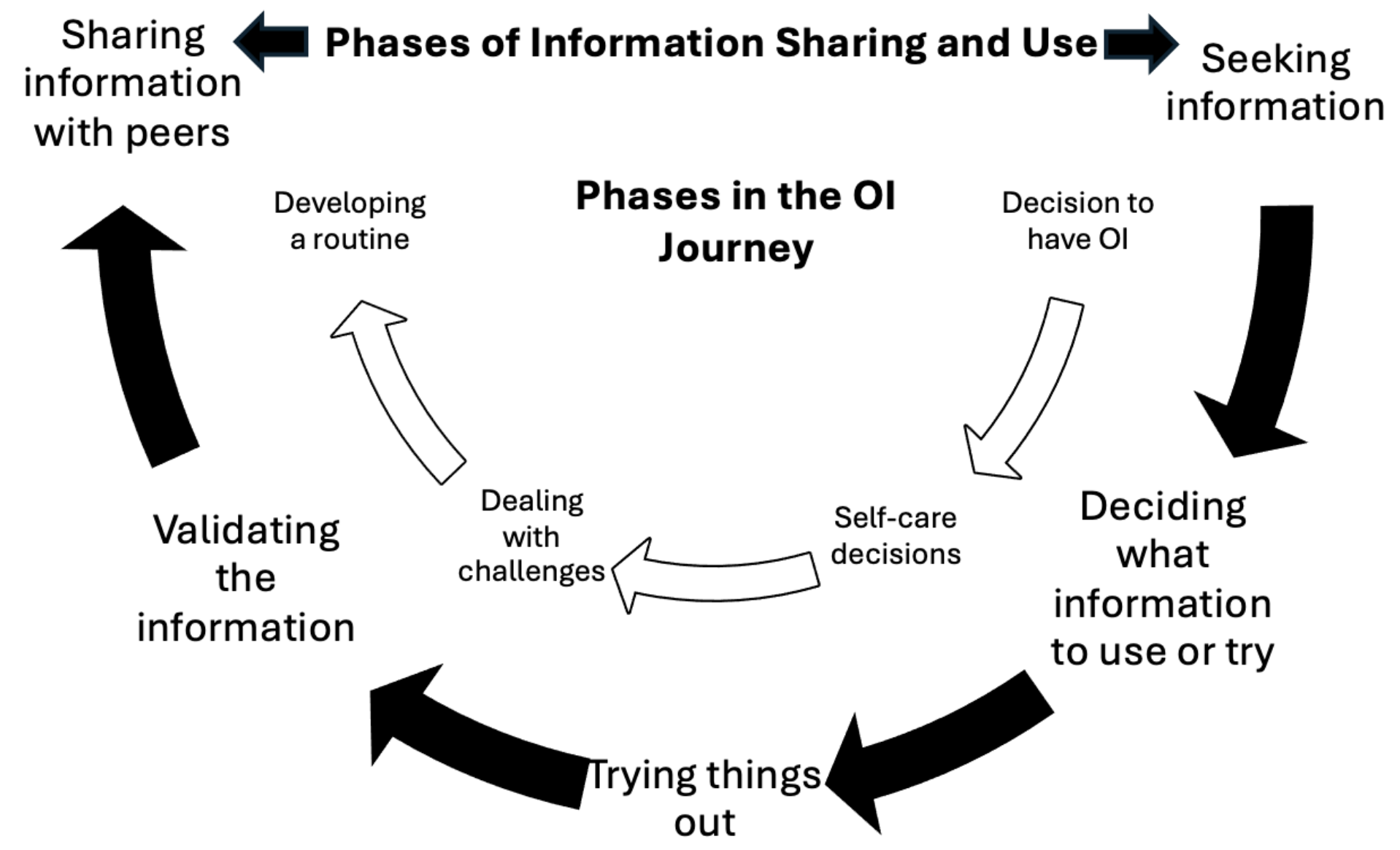

Figure 1. Information seeking and use across the phases of the OI self-management

Recommendations

Based on the findings of the study and supporting literature, we recommend online resources to support self-management for those living with OI, which includes leveraging the online communities already in place to promote education, and advocacy by and for those living with OI to promote education and awareness.

Specific strategies needed include:

- Decision Aid to support those considering OI to help inform their decision
- Evidence based information on stoma care
- Development of self-management program for those living with OI
- Healthcare professionals are uniquely positioned to promote and partner with persons living with OI to contribute to advocacy efforts

Conclusions

- All participants engaged in a multifaceted decision-making process that stemmed from their varying needs to avoid negative outcomes and engage in self-advocacy.
- Some participants described critical health literacy and critical evaluation. In the absence of this knowledge, participants had to access and screen a variety of health information and determine its credibility for integrating into their self-management practices.
- Online communities are valuable resources for healthcare providers and people seeking health information but they also present a risk of misinformation and biases.
- Healthcare professionals can leverage the presence of online communities which will enhance health education, as well as engage with these communities for partnerships and advocacy. Overall, a collaborative, interprofessional approach is needed.

References are available on request. Please email ahallara@stfx.ca or kirstenwoodend@trentu.ca