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A participatory approach to training expert patients with intellectual disabilities: towards more inclusive medical practices

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Background

In higher education in Belgium, medical students often lack sufficient exposure to the challenges faced by people with cognitive or communicative vulnerabilities, such as intellectual disabilities (Kirschner & Curry, 2009).

Moreover, the educational content on intellectual disability remains limited (Salvador-Carulla et al., 2015). However, direct interactions with patients are crucial for improving practices in inclusive healthcare (Lucassen et al., 2024).

Background

The need to increase knowledge about intellectual disabilities in training programmes is widely documented in the literature (Pelleboer-Gunnink et al., 2017; Rinaldi and Batselé, 2023; Salvador-Carulla et al., 2015).

Relational simulation is a medical education method that has been shown to be reliable, valid and feasible (Barrows, 1993; Beullens et al., 1997).

An expert patient is a person who takes part in simulated doctor/patient meetings, having been specifically trained to recreate the history, personality, behaviours and emotions of a case accurately and consistently.

Background

In the field of intellectual disability, a very small number of studies have looked at this, and the training system has not been sufficiently documented (Billon et al., 2016; Thomas et al., 2014; Watkins et al., 2016).

Aim of this study

This study aims to train individuals with intellectual disabilities as expert patients, and subsequently train medical and nursing students, while documenting the entire process.

Methodology

1

Training people with intellectual disabilities to become **expert patients**.

N = 11

2

Pre-test of the expert patient training with medical students.

N = 6 students
N = 2 expert patients

3

To test the **effectiveness of the expert patient** training with medical and nursing students.

N = 74 students (37 students per group: EG and CG)

Methodology

1

Training people with intellectual disabilities to become **expert patients**.

N = 11

Participants: we trained 11 expert patients (7 men and 4 women) in the Mons and Brussels area, Belgium

Inclusion criteria were as follows:

- Have a mild to moderate intellectual disability;
- Be aged 18 and over;
- Feel comfortable speaking and taking part in role-play;
- Be able to communicate verbally (with the help of support if necessary).

Research hypothesis

Hypothesis 1

The expert patient training **improves participants' feeling of comfort** in simulation. .

Hypothesis 2

The expert patient **training improves participants' feeling of confidence** in simulation.

Hypothesis 3

The level of knowledge of the scenario increases between session 1 and session 4.

Expert patient training

Measures

- Questionnaire to assess knowledge of the scenario to be played (in FALC)
- Visual analogue scale on feeling comfortable in the role-play
- Visual analogue scale on feeling confident in doing the role-play
- Questionnaire on training satisfaction

The researchers also completed an observation grid on the simulation skills of the participants

Expert patient training

Session 1

Getting to know each other, presentation of the research system.
Reading of the medical scenario and necessary adaptations.

Session 2

Presentation of the structure of a relational simulation.
Raising awareness of the doctor's empathy.
Training for the first medical simulations.

Session 3

Explanation of the debriefing, drawing up a list of items to help with the debriefing.
Board game.

Session 4

Dress rehearsal based on the structure of a medical simulation.

Expert patient training

Session 3

Explanation of the debriefing, drawing up a list of items to help with the debriefing.
Board game.

Results

Descriptive statistics

Participants : N = 11

7 men and 4 women

X = 39.73 years (+/-13, 39), min = 21 years - max = 64 years

	S1	S2	S3	S4
Feeling of comfort	• Comfortable = 36.36% • Not comfortable = 54.55% • Not at all comfortable = 9.09%	•Very comfortable = 18.18% •Comfortable = 63.64% •Not comfortable = 18.18%	•Very comfortable = 54.55% •Comfortable = 36.36% •Not comfortable = 9.09%	•Very comfortable = 27.27% •Comfortable = 63.64% •Not comfortable = 9.09%

Results

Descriptive statistics

	S1	S2	S3	S4
Feeling of confidence	• Sure of myself = 54.55% • Not sure of myself = 36.36% • Not at all sure of myself = 9.09%	• Very sure of myself = 45.45% • Sure of myself = 45.45% • Not sure of myself = 9.09%	• Very sure of myself = 36.36% • Sure of myself = 45.45% • Not sure of myself = 18.18%	• Very sure of myself = 27.27% • Sure of myself = 63.64% • Not sure of myself = 9.09%
Knowledge of the scenario	4.18 (.60)	4.45 (.82)	4.09 (1.04)	3.91 (1.04)
Overall satisfaction	• Good = 90.91% • Average = 9.09%	Good = 100%	Good = 100%	Good = 100%
Duration of training	• Too short = 18.18% • Good = 81.82%	Good = 90.91%	Good = 90.91%	Good = 100%

Results

Descriptive statistics

	S1	S2	S3	S4
Feeling of confidence	• Sure of myself = 54.55% • Not sure of myself = 36.36% • Not at all sure of myself = 9.09%	• Very sure of myself = 45.45% • Sure of myself = 45.45% • Not sure of myself = 9.09%	• Very sure of myself = 36.36% • Sure of myself = 45.45% • Not sure of myself = 18.18%	• Very sure of myself = 27.27% • Sure of myself = 63.64% • Not sure of myself = 9.09%
Knowledge of the scenario	4.18 (.60)	4.45 (.82)	4.09 (1.04)	3.91 (1.04)
Overall satisfaction	• Good = 90.91% • Average = 9.09%	Good = 100%	Good = 100%	Good = 100%
Duration of training	• Too short = 18.18% • Good = 81.82%	Good = 90.91%	Good = 90.91%	Good = 100%

Results

Descriptive statistics

	S1	S2	S3	S4
Level of difficulty	• Very easy = 54.55% • Easy = 36.36% • Difficul = 9.09%	• Easy = 100%	• Very easy = 45.45% • Easy = 54.55%	• Very easy = 72.73% • Facile = 27.27%
Level of comfort	• Yes, somewhat comfortable = 54.55% • Yes, very comfortable = 27.27% • No, not comfortable = 18.18%	• Yes, somewhat comfortable = 63.64% • Yes, very comfortable = 36.36%	• Yes, somewhat comfortable = 72.73% • Yes, very comfortable = 27.27%	• Yes, somewhat comfortable = 72.73% • Yes, very comfortable = 27.27%

Methodology

2

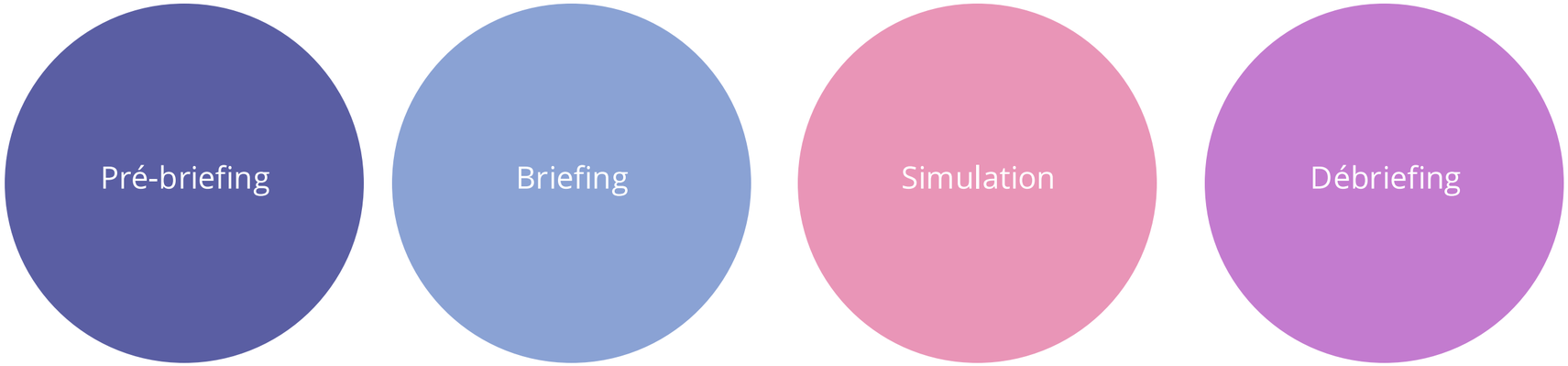
To test the **effectiveness of the expert patient** training with medical and nursing students.

N = 74 students (37 students per group: EG and CG)

Participants (research ongoing):

- medical and nursing students
- 3rd year bachelor's degree, or master's degree

Design of the relational simulation intervention:



Research hypothesis

Hypothesis 1

The expert patient training promotes **more positive representations** among students towards individuals with intellectual disabilities.

Hypothesis 2

The expert patient training **improves students' practices** towards individuals with intellectual disabilities

Hypothesis 3

The expert patient training helps **reduce social distance** between students and individuals with intellectual disabilities

Hypothesis 4

The expert patient training **increases students' empathy** (both self-reported and hetero-reported) towards individuals with intellectual disabilities

Simulation

First impressions shared by students

Lack of practice

“On a été mis en situation réelle ce qui manque dans notre parcours académique (mis à part les stages mais du coup on est déjà dans la pratique)”

The importance of debriefing

“Tout était très bien. Le débriefing est le plus important je trouve pour avoir un retour de ce qui était bien ou à améliorer”

The added value of the expert patient

“Etre avec une personne avec une déficience intellectuelle permet de se mettre en situation réelle”

Non-technical skills

“On en apprend plus sur les compétences de communication, d'empathie et sur le relationnel avec les patients”

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Thank you for your attention

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