

# The Use of Photovoice in Research With People on the Autism Spectrum: A Meta-Synthesis of the Literature

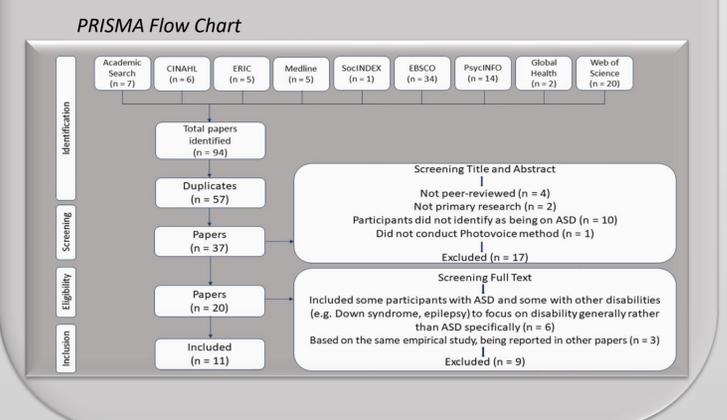
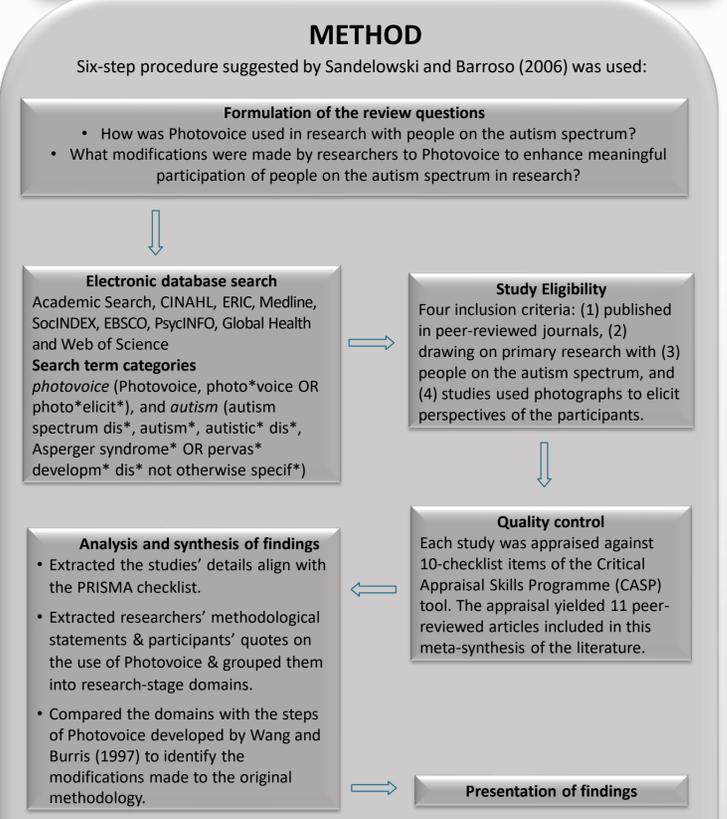
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### INTRODUCTION

- Understanding the lived experience of people on the autism spectrum from their first-hand accounts is important for generating new knowledge to inform policies, programs, and practices.
- Autism Spectrum Disorder is a developmental disorder that challenges a person’s social communication, social interaction, social-emotional reciprocity and use and understanding of nonverbal language. These challenges can make it difficult for people on the autism spectrum to participate in and communicate personal information in qualitative research studies.
- Photovoice is a methodology developed by Wang and Burris (1997), which involves research participants taking photographs and using the photographs to depict their own lived experiences.
- Photovoice has been used in some qualitative research studies with people on the autism spectrum. There is a dearth of review evidence on the ways Photovoice has been used to facilitate participation of people on the autism spectrum.

### PURPOSE OF REVIEW

To provide a meta-synthesis of the literature reporting on researchers’ uses of Photovoice to explore perspectives and first-hand experiences of people on the autism spectrum.



### RESULTS

#### Characteristics of the reviewed studies

- Conducted between 2010 and 2020, in research areas of psychology, nutrition, health sciences, and education.
- Participants: children and adolescents aged 8-17 years, or adults aged 18-25 years, on the autism spectrum, with verbal communication ability.
- Drawn on philosophical assumptions: social constructivism (ten studies), or a transformative paradigm (one study).
- Used various qualitative approaches, including ethnography, phenomenology, grounded theory, and case study.

#### Engagement of Participants on the Autism Spectrum in Research

##### Participant Recruitment and Consent

- Extensive approaches used to recruit participants (e.g., via community organizations, schools, and service centers).
- Various modes of communication used to give participants adequate and age-appropriate information (i.e., simplified- language information, visual cues, pictorial dictionary).

##### Photovoice Training and Photographic Equipment

- Three studies held only group trainings for participants, as per the guide of Wang and Burris (1997)
- Four studies modified group meetings to one-on-one training sessions with individual participants.
- Three studies included both group and individual trainings.
- Training was not held in two studies which had a small sample size and student participants purposively recruited from small schools.
- Participants used various types of cameras to take photographs (e.g., disposable cameras, digital cameras), including their own technologically up-to-date devices (i.e., smart phones, iPads, and iPods).

##### Effects?

- Offered people on the autism spectrum and their families easy access to research in a context familiar to them and appropriate with their needs.
- Offered participants an opportunity to get to know each other and brainstorm ideas about what they would take pictures for research.
- Maximized development of positive rapport and ensured that each participant understood the research process.
- Addressed difficulties of geographic distance, logistic arrangements, and varying levels of attention and social skills of participants.
- Training may not be essential, if data is gathered by acquaintances of participants.



#### Data Collection With Participants on the Autism Spectrum

Data was gathered from: the photographs taken by participants (visual data) and communication with participants about the photographs (e.g. transcripts of interviews/ focus groups). Photographs were used for prompting discussion with participants and being as visual data for analysis.

##### Capture of Photographs

Participants controlled what to photograph by taking the pictures themselves or instructing another person to take the photographs they wanted. Children participants could seek help from an adult for taking photographs.

##### Collection of Photographs

- Three studies followed this step of Wang and Burris (1997): collection and development of the photographs taken by participants before interviews or/and group discussions.
- Participants in seven studies used up-to-date devices to take, store, copy and review digital pictures for research.

##### Discussion about Photographs

Four studies conducted group discussions, as Wang and Burris (1997) outlined, and also one-on-one interviews for discussions about photographs. All studies with children used one-on-one interviews with participants to cater for their different verbal abilities and communication styles.

##### Member-checking

Participants in six studies performed member checks by reviewing the data collected and checking for accuracy of the meanings translated by researchers.

##### Effects?

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#### Time for Participants to Take Photographs

Participants in two studies took photographs within one session, while others in the remain studies had a period of time for taking photographs between sessions.

Having a time period for photographing, participants developed creativity in producing pictures for research and enjoyed autonomy in selecting images to discuss at the next encounter.



##### Effects?

- The developed prints provided shared points of reference and visual stimuli for memory and conversation of participants in discussions.
- Offered participants an opportunity to review, learn about and make primary analysis of their own visual data before discussions with researchers.

Only one study used SHOWeD – a questioning technique suggested by Wang and Burris (1997) for eliciting informantion from photographs. Researchers in other studies used semi-structured interview questions and/or verbal prompts in discussions with participants.



#### Data Analysis Approaches

Various approaches were employed for analysis of data, including the broad participatory approach described Wang and Burris (1997) and other techniques for interpreting data in qualitative research.

First, participants in all studies took part in participatory analysis of data by selecting the images that best indicated their experiences and perspectives and contextualizing the photographs with their explanation about the meaning of photographs.

Next, researchers used theoretical methods of data analysis to interpret transcripts of the interviews and the group discussions using the photographs (i.e., grounded theory, thematic analysis, interpretative phenomenological analysis).

#### Reflection of Research Participants

Four studies included direct reflection of participants on research processes.

Participant reflection helped researchers listen to participant voices to ground important implications for future studies.

Sustained meaningful participation during and post research.

#### Dissemination of Research Outcomes

Two studies included the last step of Photovoice suggested by Wang and Burris (1997): dissemination of research findings to the public through exhibitions and video clips on YouTube.

The peer-reviewed journal articles reporting findings of the reviewed studies displayed photographs, captions, quotes, narratives and examples from research participants.

Visual illustrations were helpful to represent the voices of research participants, who had difficulties in social communication or did not desire to communicate verbally.

### DISCUSSION and IMPLICATIONS

Researchers in the reviewed studies accomplished their goals by using Photovoice with the modifications to the methodology originally developed by Wang and Burris (1997), of which replications in future research will further facilitate participation of people on the autism spectrum.

The integration of visual cues into trainings has supported engagement of participants in Photovoice research procedures.

Integration of visual instructions to deliver training on Photovoice procedures for participants on the autism spectrum.

Verbal prompts, rather than the question technique SHOWeD, were used to elicit information of participants in discussions about the photographs taken for research.

Using verbal prompts rather than structured questions helps researchers encourage participants to transit from describing the photographs to other aspects of their lives and continue their discussions comfortably.

The limitation of not including people on the autism spectrum who were not able to communicate verbally was noted in five studies. This may derive from reliance of researchers on verbal communication abilities of participants in qualitative research.

Future Photovoice studies should become inclusive for people who are on the autism spectrum and with non-verbal abilities by offering them more alternatives of communication (e.g, writing about photographs or attaching pictograms to express opinions and feelings about photographs).

### CONCLUSION

- Photovoice can aid researchers to facilitate engagement and participation of people on the autism spectrum in research about their lived experiences and perspectives.
- To enhance accessibility and meaningful participation of people on the autism spectrum in research, future Photovoice studies should integrate visual cues into trainings of participants, offer participants alternative forms of communication, and include verbal prompts of researchers in discussion sessions.

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