ORIGINAL RESEARCH

Experiences of Persons with Disabilities and their Quality of Life in Two Namibian Villages

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ABSTRACT

Purpose: *The study aimed to determine the convergence and divergence of the Photovoice method and the WHOQOL-BREF assessment in integrating the experiences of persons with disabilities with Community-Based Rehabilitation (CBR) and their quality of life respectively. It also aimed to propose a practice framework for CBR programme evaluation in Namibia.*

Method: *A qualitative phenomenological design was utilised. Twelve participants were part of this study.The primary data sets used for analysis were photographs taken during a study using the Photovoice method and the results from the WHOQOL-BREF questionnaire. The Photovoice process preceded completion of the WHOQOL-BREF questionnaire. Information about the participants was gathered during the two phases. The CBR Matrix developed by the World Health Organisation was utilised to determine themes for the Photovoice method. Results of the Photovoice study were integrated with those of the WHOQOL-BREF to determine convergence and divergence.*

Results: *Notably, most participants (n=8) in both study sites had low scores regarding their quality of social relationships and environment. Furthermore, the Photovoice method revealed negative experiences of the participants regarding the environment (physical safety and security, home environment, financial resources, health and social care, access to information, recreation and leisure, physical environment, and transport). By and large there was a stronger convergence than divergence of the Photovoice method and WHOQOL-BREF assessment.*

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Conclusion and Implications: *Notwithstanding the in-depth investigation, the small sample size limits generalisability of the research findings. A study with a larger sample size is needed to confirm the findings, especially regarding the WHOQOL-BREF assessment.*

This study proposes a practice framework for CBR programme evaluation in Namibia that integrates the WHO CBR Matrix, Photovoice method, WHOQOL-BREF and highlights from the other frameworks. Further studies are required to validate the framework.

Key words: *Photovoice, WHOQOL-BREF, persons with disabilities, CBR evaluation, Namibia*

INTRODUCTION

Community-Based Rehabilitation (CBR) in Namibia was initiated in 1992 (Ministry of Health and Social Services, 2013) and officially adopted in 1997 as the main strategy for disability inclusion and rehabilitation (Government Republic of Namibia, 1997). Since then, the CBR programme has been evolving in line with global disability trends. Namibia has made significant progress in CBR monitoring and evaluation. However, CBR evaluation in Namibia is dominated by conventional quantitative methods.

Although low literacy rates amongst persons with disabilities have been reported in both low-income and high-income countries, it is more pronounced in poorer countries and thus poses a challenge on CBR evaluation frameworks which require high levels of literacy (WHO & World Bank, 2011). Furthermore, in some southern African countries (Namibia, Malawi, Zambia, Zimbabwe) between 24% - 39% of children aged 5 years and older, with disabilities, have never attended school (WHO & World Bank, 2011). To this end, there is a need to investigate mixed evaluation research methods: methods that are complementary and methods which require the participation of persons with disabilities in the evaluation process.

Against the backdrop of mixed-method CBR evaluation, the authors of this study undertook to develop and propose a monitoring and evaluation framework that could be used to assess lived experiences of persons with disabilities regarding their quality of life. Preparatory phases to develop this framework involved a number of investigations to provide a comprehensive background as outlined below.

A review of policies and legislations in Namibia (Shumba & Moodley, 2018a) identified CBR as underpinning key strategy for delivery of disability and rehabilitation services in the country. Shumba and Moodley (2018b) also confirmed the need to explore the experiences of persons with disabilities in CBR programmes using appropriate qualitative evaluation tools. A scoping review established that Photovoice has the potential to be utilised as a qualitative evaluation tool for effectively eliciting the experiences of persons with disabilities on a CBR programme (Shumba & Moodley, 2018c).

Photovoice is a method that can be used by vulnerable populations including persons with disabilities to voice their concerns and enable them in their advocacy efforts, and as such better reach policy-makers. Vulnerable populations use photographs captured in Photovoice to facilitate interpretation of community concerns and this promotes policy change (Wang & Burris, 1997). However, Photovoice has evolved since its initial conceptualisation and has extended to be used as a qualitative research tool for many purposes including a participatory evaluation tool, a retrospective evaluation method (Kramer et al., 2010) and a needs assessment tool (Findholt, Michael & Davis, 2011).

Although Photovoice has the potential to elicit the experiences of persons with disabilities, it does not provide a measure for quality of life. To this end, the World Report on Disability recommended evaluation tools that can simultaneously measure the experiences of persons with disabilities and their quality of life.

'To understand the lived experiences of people with disabilities, more qualitative research is required. Measures of the lived experience of disability need to be coupled with measurements of the well-being and quality of life of people with disabilities' (WHO & World Bank, 2011).

Thus, to confirm the elicited experiences of persons with disabilities, the measurement of quality of life becomes critical. A number of instruments can measure the quality of life for persons with disabilities. One relevant instrument is the Quality of Life (WHOQOL) instrument (WHOQOL Group, 1995) developed by the World Health Organisation, and intended to assess people's 'perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (World Health Organisation, 1998). It can be used to establish (baseline) scores in a range of areas including effectiveness of treatments, audit, policy-making, and research. Furthermore, it can be utilised to determine changes in quality of life

during the course of interventions, research, and policy-making (World Health Organisation, 1998). The WHOQOL instrument has two forms: the WHOQOL-100 with 100 questions of assessment and the WHOQOL-BREF with an abbreviated 26-item assessment. The WHOQOL-BREF is used when there is a group of participants who do not have enough time and should not be over-burdened. Both instruments have various domains and sub-domains to produce a multi-dimensional profile of scores including environmental, psychological, physical health and social relationships. In addition to the above-mentioned quality of life domains, the WHOQOL-BREF measures other aspects including the quality of sexual life, which in most instances is not measured with other instruments. WHOQOL-BREF was developed in 29 language versions, embracing 15 cultural settings (World Health Organisation, 1998).

A feasibility study (Shumba & Moodley, 2018d) was conducted to assess the potential of utilising the WHOQOL-BREF questionnaire following the Photovoice method to quantitatively assess the baseline quality of life of persons with disabilities. This study (Shumba & Moodley, 2018d) identified critical issues to be considered in the implementation of future studies, utilising a combination of Photovoice and the WHOQOL-BREF. These refer to four broad feasibility criteria of classifications, i.e., process, resources, management, and scientific processes, as mentioned by Van Teijlingen et al (2001) in a study done to establish the rationale of feasibility studies. These four feasibility criteria are crucial in mapping key requirements for future main studies. A detailed explanation of each feasibility criteria is provided in Table 1.

Table 1: Study Criteria

Criteria	**Issue assessed**	**Lessons learnt in feasibility study by Shumba and Moodley** (2018a)	**Final criteria for current study**
1. Process: Assessing the feasibility of the processes that are key to Photovoice and WHOQOL-BREF assessment	Study site - CBR programme	The CBR volunteers who participated were active and helped in identifying and motivating other participants	-Functional CBR committee and CBR volunteers with at least 2 years of CBR programme implementation were selected -Two different geographical study sites were selected to ensure diversity in terrain, culture and tribal influence

	Participant characteristics	Including caregivers/family members/siblings of persons with disabilities gives skewed perspectives of experiences and quality of persons with disabilities. Furthermore, persons with mental illness and intellectual disabilities require rigorous selection and particular attention to ethical processes	-Included: people with physical disabilities, able to use a camera and describe/explain a picture, willing to remain involved in the study for one month -Excluded: caregivers/family/ siblings of persons with disabilities, persons below 18 years of age, intellectual disabilities, mental illness, highly dependent on medical care, HIV positive and previous traumatic war experiences or stressful life circumstances
	Research assistant	Persons with hearing impairment were excluded from the study as both researcher and research assistant had no sign language skills	Senior Rehabilitation Officer for each region was selected as follows: -Have at least 3 years of CBR experience -Have been working for at least 2 years in CBR programme in that region -Able to speak the local language of that area -Well-versed with local culture -Have basic sign language skills.
	Retention of participants	Retention rate was 6 out of 9 (66.67%). Reasons for drop out were lack of incentives and poor communication with research assistant	- Availed of airtime for group leader of participants for constant communication with researcher and research assistant -Certificates of completion and non-monetary incentives including T-shirts were given
	Understanding the data collection tools - Photovoice technique and WHOQOL-BREF	- Though explained by researcher, the research assistant's understanding of Photovoice method and WHOQOL-BREF was poor	- Research assistants trained and oriented on the Photovoice method and WHOQOL-BREF before selecting participants
	Adherence to Photovoice ethical issues	- Participants had challenges of getting signatures for providing consent to take photographs of human subjects - most of the participants and subjects could not read and write	-Subjects to be photographed or their caregivers provided an "X" as indication of signature and then the researcher/ research assistant followed up these subjects to confirm consent
2. Resources: Forecast time and resource problems that can occur during the main study	Process taking photos and having to share their thoughts about the photos	-Some participants took time to recall why they took the photo because of the time lag in processing the cameras and interviewing	-Disposable cameras were processed immediately after photography assignment and interviewing was done within 2 days
	Establish time needed to fill out the WHOQOL-BREF questionnaire	-It took roughly 40 minutes to an hour for filling out the WHOQOL-BREF questionnaire as participants needed to be assisted -Participants were already tired of filling the WHOQOL-BREF questionnaire following the Photovoice interview	-A break was taken between Photovoice interviewing and filling out the WHOQOL-BREF questionnaire

	Type and quantity of language version of the WHOQOL-BREF questionnaires needed	-Most participants could understand well the Afrikaans WHOQOL-BREF version	- Copies of both the English and Afrikaans versions were printed
	Place and cost of Braille or large print questionnaires	-Braille material was not available for one participant with visual impairment and thus relied on interpretation	-A resource centre was asked to provide Braille documents for blind and visually impaired participants
	Type of camera to use	-Disposable cameras allowed participants to take a limited number of photographs, these cameras are strong and cheap to purchase -Place for processing the cameras (film) was easily accessed -The quality of some pictures taken was fair	-Disposable cameras were ideal in rural settings -Established the proximity of resources for processing the disposable cameras (film) -Participants were trained in photographic techniques to improve the picture quality
	Contingency plans for cameras	-One of the participants reported a broken camera. Research assistant had to replace the camera without delay	Established contingency plans in case participants' cameras are broken or lost before processing
	Distance, transport and time to reach study site	-The researcher underestimated the time needed to reach the research site and the type of transport needed	-In selecting study site, the following were considered: transport, distance and time needed to reach the site
3. Management: Establishing potential human and data management problems	Challenges of participants during Photovoice method and in filling WHOQOL-BREF questionnaire	-Some participants reported lack of transport to reach places where they wanted to take photos -Most participants needed privacy to answer some questions on the WHOQOL-BREF questionnaire	-Researchers continuously provided support to participants during the Photovoice method -Transport arrangements were made for some participants to access photo opportunities -Privacy and confidentiality in administering the WHOQOL-BREF questionnaire were ensured
	Number of photograph assignments and individual interviews	-Two photograph assignments and individual interviews were conducted and this ensured refinement of data	- Two photograph assignments and individual interviews were conducted to ensure that data was adequate
	Data storage	-Researcher stored the data in an encrypted file on the computer	-Data was stored in a secure, locked digital safe and on an encrypted file on computers -Data will be disposed of by shredding after 5 years
	Data dissemination	-Participants' and subjects' names were not used and faces were not shown	Names of participants were not used, and participants' faces on photographs were not shown

4.Scientific: Assessment of trustworthiness, response to Photovoice and WHOQOL-BREF questionnaire	Sample size	-6 participants were an ideal number for the Photovoice method and administering WHOQOL-BREF questionnaire	-Sample of 6-10 is ideal (Wang and Burris, 1997) -However, to test internal consistency of the WHOQOL-BREF questionnaire a sample >200 is ideal (WHOQOL Group, 1996) -Since this was an integration of two methods and since Photovoice preceded WHOQOL-BREF, the sample size for Photovoice was the same as that of WHOQOL-BREF -Eight participants per each study site were purposively selected with the help of Senior Rehabilitation Officer and utilising the participant characteristics as set out above
	Trustworthiness	-Lincoln and Guba model of trustworthiness was applied for Photovoice method. This ensured credibility, transferability, dependability, and confirmability	- Lincoln and Guba model of trustworthiness was applied when utilising the Photovoice method
	Identification of themes	Participants identified their own themes and sub-themes	CBR Matrix of the WHO was utilised as a framework to underpin identification of themes and sub-themes
	Duration of study	-This study lasted two weeks. However, WHOQOL-BREF questionnaire was administered to establish baseline on quality of life	- Duration of Photovoice method was determined by data saturation -The study lasted one month - For the current study, WHOQOL-BREF questionnaire was administered to establish baseline on quality of life -To measure change in quality of life as a result of CBR programme implementation, the WHOQOL-BREF can be administered over a period of 2 years
	Multiple study centres	-Only one site was utilised	-Photovoice and WHOQOL-BREF were implemented in conjunction in two study sites, comparing results
	Feasibility of combining the Photovoice method and WHOQOL-BREF questionnaire	-Utilising the same participants for both Photovoice and WHOQOL-BREF allowed for comparison and confirmation of Photovoice findings with WHOQOL-BREF	The same participants that were utilised in Photovoice method completed the WHO-BREF to allow comparison and confirmation of Photovoice findings with WHOQOL-BREF

Source: Adapted from Van Teijlingen et al(2001); Shumba and Moodley (2018a)

Objective

Utilising a combination of Photovoice and WHOQOL-BREF, the current study aimed to determine the convergence and divergence of Photovoice and WHOQOL-BREF in reviewing the experiences and quality of life, respectively, of persons with disabilities. Utilising qualitative content analysis of the participants' comments

about their CBR experiences in the Photovoice method and matching them with their respective quality of life results from the WHOQOL-BREF questionnaire, a convergence or divergence of their CBR experiences and quality of life was determined. Furthermore, the study aimed to propose a practice framework for CBR programme evaluation in Namibia.

METHOD

Study Design

The study utilised a qualitative phenomenological design. It describes and explores the integration of information of real-life experiences of persons with disabilities via the photographs taken by the participants, with an interview study that offers insight into their quality of life. This study took place in the context of a Community-Based Rehabilitation programme being implemented in selected rural communities of Namibia. The study methodology was guided by a set of study criteria developed by Van Teijlingen (2001) which was further adapted by the authors Shumba and Moodley (2018d) in their feasibility study.

Study Setting

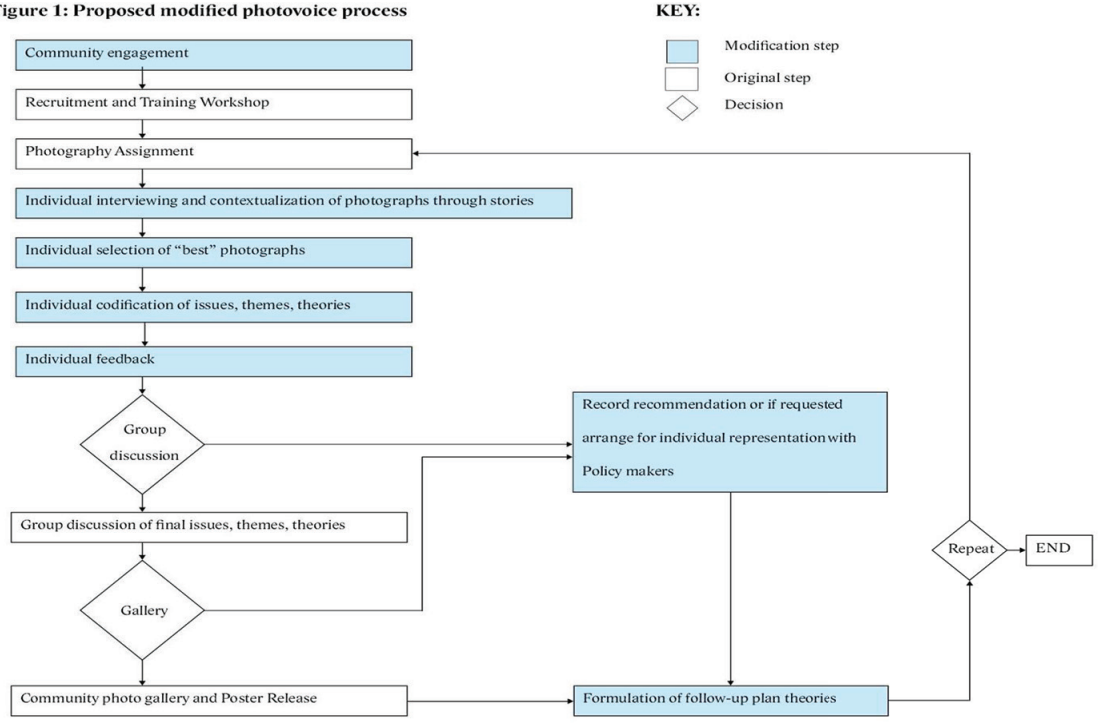
Two CBR study sites were selected, with diverse culture, terrain and disabilities. Stampriet is 350 km south of Windhoek and Otavi is about 440 km north of Windhoek. The two sites have different tribes with Stampriet having a predominately Nama and Damara speaking population, and Otavi with a predominately Otjiherero speaking population. Stampriet is administered under a village council and Otavi is administered under a town council.

Data Collection and Analysis

Data collection and analysis were conducted simultaneously. The primary data set used for analysis comprised photographs taken by the participants as well as the results from the WHOQOL-BREF questionnaire. The original WHOQOL-BREF English language and Afrikaans language versions were used, depending on the language each participant felt comfortable with. The Photovoice method preceded completion of the WHOQOL-BREF. The participants were involved in both phases of this study to allow for comparison and integration of information about lived experiences derived from the Photovoice method and their quality of life determined from the WHOQOL-BREF assessment.

Photovoice Method - Data was collected and analysed utilising the modified Photovoice method by Shumba and Moodley (2018c) which is illustrated in Figure 1. All individual interviews were transcribed verbatim, and the constant comparative approach (Patton, 2002) was utilised during the data analysis. Initially, there were individual interviews where participants were required to present their best 5 photographs and provide any explanation or details that they felt were very important. After each interview, a validation with each participant was conducted to confirm and increase credibility of the findings. Besides, the researcher and research assistant discussed the selected photographs with the participant, and compared these with their transcript to check if there was any information that required further in-depth probing.

Figure 1: Proposed modified photovoice process



After the Photovoice study a focus group workshop was held with all participants, to decide on themes and sub-themes for organising and clustering the photographs. Direct content analysis was employed where the WHO CBR Matrix (WHO, UNESCO, ILO & IDDC, 2010) was used as a framework to determine the themes and sub-themes. The WHO CBR Matrix was selected because it strongly emphasises the need for involvement of the community in CBR programming, and is resolutely underpinned by the United Nations Conventions on the Rights

of Persons with Disabilities (United Nations, 2006) which promotes the human rights model of disability.

At the beginning of the focus group workshop, the WHO CBR Matrix was shared with the participants by the researcher, and agreement was reached to utilise it for determining themes and sub-themes and organising the selected photographs. Each participant presented his or her photographs, and this was followed by a group discussion. Agreement on final themes was arrived at through group discussion.The researcher deemed the data saturated when no new statements were made regarding the meaning of the photographs and all the participants agreed on what was discussed. A detailed explanation of the whole Photovoice process is shown in Table 2.

Table 2: Procedure for Data Collection and Analysis

Step	Procedure	Duration
1.Community engagement	The research assistant organised a meeting with the local Councillor to discuss the purpose of the pilot Photovoice project in their community. Upon gaining approval from the Councillor, a date was set to meet with persons with disabilities who are beneficiaries of the CBR programme, CBR volunteers participating in CBR programme and caregivers/family members of persons with disabilities, to gain support and understanding of the Photovoice project.	½ Day
2. Recruitment and training	For each CBR site, eight participants with diverse backgrounds were purposively selected for training. This training also served as a platform for participants to introduce themselves and get to know one another. The training discussed the following aspects: Photovoice process; group objectives; informed consent to participate and for photography subjects: how to use the camera; the basics on how to take photographs; general guidelines for photographs; special consideration/ ethical considerations when photographing human subjects. These training aspects are detailed below: • Photovoice process Underlying issues around the use of the cameras in the community were discussed and emphasis was placed on focusing on the use of the camera and ethical concerns around taking photographs and the potential risks that may be faced as photographers. • Project objectives Participants were informed of the objectives of the pilot Photovoice study and that the study was for academic purposes only. It was important to develop framing questions to serve as guidelines for participants in identifying potential photographic subjects that would be meaningful for them and consistent with the objectives of the research. Instead of using the "SHOWeD" technique by Wang and Burris (1997) that was used in the preliminary assessment (Shumba & Moodley, 2017c), the team adopted the personal-questions approach by McIntyre (2003). The McIntyre approach empowers participants and assists them in codifying the photographs.	

	• Informed consent to participate The researcher and research assistant guided participants through the informed consent form. Participants were informed that participation is voluntary and that they may discontinue at any time during the study. • Photography The researcher trained the participants on how to: use the camera; take photographs in relation to the subject matter, taking into account special consideration for human subjects. Each participant was then issued with the following materials: ❖ 1 disposable camera (27 exposure film) ❖ Subject consent forms for the photographed subjects to sign and confirm consent	½ Day
3. Photography assignment	This part of the project involved taking of photographs by the participants, collection of the cameras and signed consent forms, development of photographs, and reflection. Participants were given six days to take photographs and to return their cameras and the subject release forms to the research assistant, who then sent them to the researcher. About midway through the 6 days, the research assistant telephonically reminded the participants of their deadlines and offered encouragement and advice where necessary. Each study site had a participant group leader who would constantly update the research assistant on the progress. After six days, the researcher received the cameras and had the photographs processed (developed). Each participant's set of photographs were saved and coded on separate compact discs (CDs). This master set of CDs was retained in safe-keeping by the researcher. Processing of the photographs took a day.	7 days
4. Individual interview, selection of "best" photographs, codification and feedback	• Individual Interviews During week two, the researcher and research assistant returned to the site with the processed photographs. Participants were requested to come to the Councillor's office at selected times for individual interviews. • Individual selection of "best" photographs Each participant was allocated time for individual selection of the "best" 5 photographs. These best photographs were supposed to describe their experiences regarding the CBR programme. • Individual codification of issues, themes, and stories The researcher requested each participant to club together photographs they had selected with similar meaning and identify a theme. Those belonging to one theme but of a sub-category were assigned to a sub-theme. McIntyre's(2003) personal questions were utilised: • Personal questions ▪ What is the meaning of these photographs to you? ▪ What is the relationship between the content of the photographs and how you perceive Community- Based Rehabilitation? ▪ Do you think the photographs are reflecting issues that are representative of the experiences of CBR programme by other community members? • Individual feedback During the feedback session, participants shared their challenges and achievements during the Photovoice process. At this point an atmosphere of trust allowed participants to express themselves freely. Participants also proposed other photographs that they could have taken but did not for various reasons.	3 days

	NB: On completion of individual feedback sessions, participants were invited to the local Councillor's office to share their selected photographs with the other participants in a group discussion. The aim of the group discussion was to select the final photographs that best represent a collective story of the CBR programme. However, participants were informed that the group discussion was voluntary, and they had the option not to share their stories in a larger group. All participants agreed to participate in the group discussion. Following these sessions, the researcher and research assistant transcribed verbatim all audio recordings, reflected on participants` selected photographs and debriefed on emerging themes.	
5. Group discussion of final issues, themes and stories	▪ Feedback on each others' photographs On arrival at the Councillor's office, the group discussion participants were encouraged to circulate in the room, to view and reflect on all the photographs that were displayed on the walls, and to talk to other participants about their experience of taking and selecting photographs. At the same time, the researcher circulated among the participants to ask probing questions and take field notes. • Presentation of the WHO CBR Matrix underpinning the identification of themes At the beginning of the group workshop, the WHO CBR Matrix was presented to the participants as the framework underpinning the identification of themes for member check, accuracy and validation. • Sharing of individual issues and presentation of themes The researcher then used an LCD projector to display the selected photographs on a big board for each participant. All participants were allocated 20 minutes each to present their findings and were instructed to link specific pictures with the WHO CBR Matrix. The other participants were requested to refrain from asking questions during this process; they could however make a note of their clarifying questions and their own stories to share later in the final discussions.	1 day
	▪ Group consensus of themes This was done through full group discussion to ensure that the themes were represented and that all alternatives were explored. At this stage all participants could share their individual and collective experiences as they related to specific photographs, revising the underlying issues and themes. Consensus on the final themes and sub-themes was reached through discussion. The researcher deemed the data saturated when no new statements, regarding the meaning of the photographs, were made and all the participants reached an agreement on what was discussed. NB: The discussions and the workshop were closed with some discussion questions: ❖ What did you learn about yourself, this group, and the community? ❖ What is the best way to present the findings? Do you prefer a photo gallery or a poster release? ❖ Can Photovoice be implemented on a larger scale in other regions? Suggest improvements to the Photovoice process. At both CBR sites the participants opted for a poster release. The researcher then provided each participant with a CD with all photographs and hard copies of the photographs to distribute to their subjects as a token of appreciation. Participants were invited to share their experiences and photographs through a poster release. They were informed that this was voluntary, and they had the right to refuse. Most participants indicated the desire to create a poster for use during awareness-raising of CBR activities and commemoration of international and national disability days. The researcher and research assistant reflected on participants` selected photographs and debrief on final themes.	

6. Completion of WHOQOL questionnaire	Upon completion of the group discussion, the participants were requested to complete the WHOQOL-BREF questionnaire by basing it on their life experiences during the past 2 years. The researcher administered the WHOQOL-BREF questionnaires that were already translated into Afrikaans and English. All participants in both sites were conversant with either English or Afrikaans. The researcher and research assistant supervised the completion of the English or Afrikaans WHOQOL-BREF questionnaire. The completed WHOQOL-BREF questionnaires were collected for manual calculation by the researcher, following the steps and formulas stipulated by the WHOQOL-BREF Instructions Manual (WHOQOL Group, 1996).	
7. Poster release	The researcher developed the first draft of the poster and sent it to the participants for inputs through the research assistant. Inputs were given from both CBR sites and a final poster was released. Several copies were made for each CBR site.	14 days
8. Formulation of follow-up plan	The researcher asked each research assistant to meet the participants to develop an action plan to tackle some of the issues of concern identified.	Undefined

Source: Adapted from Wang and Burris (1997)

WHOQOL Questionnaire - After the Photovoice process was completed, the participants were requested to fill out the WHOQOL-BREF questionnaire on the basis of their life experiences during the past 2 years. The researcher administered the WHOQOL-BREF questionnaires that were already translated into Afrikaans and English. Participants chose the language they were conversant with - either English or Afrikaans. The researcher and research assistant supervised the completion of the selected questionnaire.

Data from the WHOQOL-BREF questionnaire was manually calculated following the guidelines and formulas stipulated in the Instruction Manual by converting the domain scores to transformed scores comparable with WHOQOL-100 (4 - 20 scale and 0 - 100 scale) as shown in Table 4 on page 11 of the WHOQOL-BREF Instructions Manual (WHOQOL Group, 1996).

Ethics Approval

Ethics approval was obtained from the Human Sciences Ethics Research Committee of the University of KwaZulu-Natal (Reference No: HSS/0646/015D) and the Ministry of Health and Social Services in Namibia approved to conduct this research (17/3/3).

RESULTS

The findings are presented under the following two headings:

1) Participants' characteristics, and
2) Degree of convergence and divergence between the Photovoice method and WHOQOL-BREF assessment.

Participants' Characteristics

The participants' demographics and reasons for drop out from this study are shown in Table 3. Of the initial 16 participants, 12 completed the study (7 in Otavi and 5 in Stampriet). Participants' ages ranged from 21-77 years and there were more females (n=10) than males (n=6) among them. The majority of selected participants had physical disabilities (n=12), visual impairments (n=3), and only one individual had a mental illness. Most participants were CBR volunteers participating in CBR programmes.

Table 3: Participants' Characteristics and Reasons for Drop Out

Participant Code	Study Area	Type of Disability	Age	Gender	Highest Education received	Completed study	Reason for Drop Out
O1	Otavi	Physical (lower limb paralysis)	77	Male	None	Yes	_____
O2	Otavi	Physical (lower limb amputation)	64	Male	Primary school	Yes	_____
O3	Otavi	Physical (lower limbs)	52	Female	Primary school	Yes	_____
O4	Otavi	Visual impairment (low vision)	58	Female	Secondary school	Yes	_____
O5	Otavi	Physical (lower limbs)	49	Female	Primary school	Yes	_____
O6	Otavi	Physical (upper limb and lower limb paralysis)	76	Male	Primary school	Yes	_____
O7	Otavi	Physical (lower limb amputation)	51	Male	Secondary school	Yes	_____
O8	Otavi	Visual impairment (blind)	41	Female	None	No	Took photos and lost interest before interviewing. Needed assistance in photography
S1	Stampriet	Physical (lower limb paralysis)	29	Male	None	Yes	_____
S2	Stampriet	Physical (cerebral palsy)	48	Male	None	Yes	_____
S3	Stampriet	Physical (cerebral palsy)	21	Female	Primary school	No	Took photos and lost interest in interviewing
S4	Stampriet	Physical (lower limbs paralysis)	44	Female	Secondary school	Yes	_____
S5	Stampriet	Physical (upper left limb amputation)	26	Female	Secondary school	Yes	_____
S6	Stampriet	Physical (blind)	24	Female	Secondary school	No	Was taken by family members to another town before interviewing
S7	Stampriet	Physical (left upper limb paralysis)	34	Female	Secondary school	Yes	_____
S8	Stampriet	Mental illness	47	Female	Primary school	No	Took a lot of photos on one item (obsessive tendency) and lost interest for interviewing

Convergence and Divergence of Photovoice Method and WHOQOL-BREF

Table 4 displays the convergence and divergence of results from the Photovoice study and the WHOQOL-BREF study. As depicted in Table 4, all participants in Otavi (n=7) were moderately satisfied with their overall quality of health. In contrast, all participants in Stampriet (n=5) were satisfied with their overall quality of health. Notably, most participants (n=8) in both study sites had low scores regarding their quality of relationships and social environment. It is noteworthy that Question 21, "How satisfied are you with your sex life?" did not elicit responses from almost all participants (n=11). This may be attributed to cultural norms where questions on sexual life are difficult to ask and the responses are restricted. The Photovoice method revealed negative experiences regarding environment (physical safety and security, home environment, financial resources, health and social care, access to information, recreation and leisure, physical environment, and transport). Most participants in both study sites reported that their quality of physical health and psychological well-being was fair.

Convergence was shown for example on S7 (Stampriet Participant 7) who had a high score on the overall quality of health (81%) and also expressed satisfaction with services provided at the local clinic. On the other hand, divergence was indicated with Stampriet Participant 4 who recorded a high score for psychological well-being (81%) but expressed negative experiences in her life. In general, there was a stronger convergence than divergence between the two methods.

Table 4: Combined Participants' WHOQOL-BREF and Photovoice Results

Participant Code	Domain 1: Physical health	Domain 2 Psychological	Domain 3: Social relationships	Domain 4: Environment	Overall Quality of Health	Overall Quality of Life	Photovoice Participants' responses	Convergence of Photovoice & WHOQOL-BREF	Divergence of Photovoice & WHOQOL-BREF
	0-100	0-100	0-100	0-100					
O1	44	19	44	25	3	3	*"The CBR programme has been working hard to secure wheelchairs for persons with disabilities. The CBR programme sourced a donation of wheelchairs from Ohorongo Cement Company for person with disabilities in this area. However the wheelchair is now too small to allow him to sit comfortably. As CBR volunteers we referred him for new measurements at the medical rehabilitation worker to get a new wheelchair"* (O1).	-Environment -Physical Health	-Psychological

O2	44	56	56	38	3	2	*"CBR volunteers referred him for physiotherapy. He has been receiving physiotherapy services and also received a wheelchair… as CBR volunteers we help him with some exercises at home…we feel we are helping him improve his health"* (O2).	-Psychological -Social relationships	-Overall quality of health
O3	38	56	44	50	3	3	*"This girl was born without one arm and has 2 kids but doesn't know the father of the kids. She went to school but dropped out early in primary education because of discrimination and has since refused to return. I* (CBR volunteer) *helped her to acquire a national I.D and disability grant. I am worried that she will continue being impregnated and abused by men and would like to refer her for adult education"* (O3).	-Psychological -Social relationships	
O4	44	81	44	63	2	3	*"I am taking care of this child with a disability and I also have a disability. He has athetoid cerebral palsy and I have challenges with balance in walking. I can't look for a job because this child needs my attention every minute. I always wish the government can also help persons like us within personal assistances so that we can also be able to seek employment and have time to socialise"* (O4).	-Overall quality of health	-Psychological -Environment
O5	81	56	44	44	3	2	*"This is a community toilet which used to be cleaned by the Council before the people were relocated to another location. In the new location there are no toilets and people come to this toilet. It is not clean and on top of that it is blocked and sewerage is everywhere. Even us persons with disabilities, including the visually impaired, use this toilet. We are very worried that this is a health hazard to this community"* (O5).	-Environment -Overall quality of life	-Physical health

O6	63	63	50	31	2	3	*"I* (CBR volunteer) *feel sorry and it hurt me that this man can't push his wheelchair and needs assistance every time to get out of his home especially when he is in need of medical treatment. The ambulances at the clinic don't pick up patients even those that are seriously ill. The clinic needs to consider the needs of person with disabilities, especially those who have mobility problems"* (O6).	-Environment -Overall quality of health	
O7	13	31	0	19	2	2	*"This is the town council, one of our public buildings, which is not accessible. There are a lot of stairs here and no ramp or lift. This is the same with the post office and Telecom… We* (CBR volunteers) *discussed this with the management of the different buildings and they appreciated the advice and promised to improve the accessibility"* (O7).	-Environment -Overall quality of life	-Social relationships
S1	56	81	56	31	3	3	*"I am grateful that the village Council built this toilet for me but unfortunately it is not accessible for me. I can't use it and when I feel like going to the toilet I go to the bush. Imagine the challenge I have in getting off the wheelchair in the bush and getting back. It's really painful and very risky for me. I have since reported this matter to the Councillor`s office but there is no action. My sister who is also a CBR volunteer has supported me several times but still we haven't yet won"* (S1).	-Environment -Physical health	-Psychological
S2	50	44	50	56	4	3	*"I am using a wheelchair and I need assistance always to get in and out of my house as well as use my toilet. When I am left alone at home I can't use the toilet and go out of the house. The CBR programme has helped me to lobby with local business people to help with building a ramp at this door as well as renovating my toilet to make it accessible"* (S2).	-Psychological -Social relationships -Physical health	

S4	56	50	44	50	4	3	*"It is so sad that we* (persons with a disability) *have such a school which neither enrols a child with a wheelchair nor a child who is deaf. It* (the school) *does not have ramps for wheelchairs or teachers for deaf children. These children are referred to Mariental or Windhoek where most times they don't have anyone to stay with… .."*(S4).	-Social relationships -Psychological -Environment	
S5	56	56	44	44	3	2	*"This is a primary school in my* (CBR volunteer) *area which is not accessible to persons with intellectual disabilities. It does not have a special class to cater for children with intellectual disabilities. All children with intellectual disabilities are referred to Mariental or Windhoek"* (S5).	-Environment	- Overall quality of life
S7	69	81	44	44	4	3	*"We* (CBR volunteers) *are happy with the services at this clinic. The nurses attend to you in a timely manner and the building is accessible in terms of toilets and the passages for persons with disabilities"* (S7).	-Psychological -Physical health -Overall quality of health	-Environment

DISCUSSION

Notably, the ultimate goal of the CBR strategy is to improve the quality of life of persons with disabilities, yet most CBR evaluation frameworks fail to measure this critical aspect. The WHOQOL-BREF assessment offered an opportunity to measure the (baseline) quality of life of persons with disabilities who were involved in the Photovoice study.

Importantly, the scope of the current study only allowed for the measurement of the baseline quality of life and did not measure changes in quality of life due to the complexity of the process and limited time. Thus, future CBR research could consider longitudinally measuring changes in quality of life and CBR experiences, especially in new areas where CBR still needs to be implemented. However, some researchers have questioned whether there is value in repeatedly measuring some quality of life domains over time or just at baseline (Li, 2004). Domains such as psychological and social relationships may not change significantly over a short period of time due to diversity in type and age of persons with disabilities. Nevertheless, integrating the information about experiences of

persons with disabilities with their quality of life can help to get better knowledge and information about successes or failures of CBR. If more evidence can be provided about improved quality of life of persons with disabilities as a result of CBR interventions, this may give justification to intensify advocacy for CBR as well as soliciting for more funding for CBR programming.

The WHOQOL-BREF assessment offered an opportunity to measure the (baseline) quality of life of persons with disabilities who were involved in the Photovoice method. The overall quality of life of all participants in both study areas ranged from poor to neither poor nor good. Notably most participants (n=8) gave low scores in the social domain and environmental domain (WHOQOL Group, 1996). Findings from studies like this one can help CBR evaluators and planners to become aware of areas of interventions that require priority in CBR programming.

It is noteworthy that the low scores recorded in the social relationships domain were mainly due to most participants' reluctance to answer one of the items (Question 21) that explored their sexual satisfaction. This finding can be attributed to the larger number of female participants than males in the study. Sexual satisfaction tends to be determined by the type of disability, gender, and severity of the disability. Addlakha et al (2017) argued that sexual desire and satisfaction can be affected by a particular disability, governed by culture, socialisation, socio-economic class, and gender. Furthermore, women with disabilities often suffer lack of physical identity and mutual sexual experience, which accounts for their low sexual satisfaction. One of the issues that may be at stake in using a validated tool and certainly with a tool such as the WHOQOL-BREF - which uses scores - is the fact that if changes are being made (e.g., questions are changed, deleted or structurally not answered) one has to re-establish that the questionnaire is still reliable and valid. The fact that the question on sexuality was not answered by most participants influences the scores, although the instructions about computing scores make provision for incomplete assessments as long as the missing scores do not exceed 20%. However, this is not the case in the current study as one question only, in the social relationship domain, was not answered adequately. Given the importance of sexuality, a possible review of the WHO CBR Guidelines and national CBR policies should consider emphasising issues around sexual reproductive health rights.

The WHOQOL-BREF questionnaire was not user-friendly for some participants because of their low literacy skills as well as their non-English or Afrikaans-

speaking background. This resulted in some of them being unable to comprehend some of the WHOQOL–BREF assessment questions. In such cases the research team assisted in interpretation. This could potentially result in missed opportunities of correctly interpreting "big issues'', such as livelihood opportunities, that were important to participants. One of the key issues that some participants expressed concern about was opportunities for vocational training and income- generating projects.

The integration of Photovoice findings with the WHOQOL-BREF assessment revealed distinct social realities and milestones of the person's quality of life. The Photovoice method allows persons with disabilities to reveal hidden but pertinent realities that are often missed by traditional data collection methods and are sometimes disregarded by family members, including social and sexual relationships. For example, the Photovoice study revealed teenage and unwanted pregnancy, particularly amongst persons with mental illness. However, the issue of sexuality was not adequately revealed by the WHOQOL-BREF assessment. Question 21 - "How satisfied are you with your sex life?" - did not elicit responses from almost all participants (n=11). This might be attributed to the social taboo associated with talking about sexuality in public. In this current study, HIV/AIDS and sexual reproduction have emerged as less prevalent issues for persons with disabilities. It thus could mean that the CBR programme in Namibia should consider placing more emphasis on HIV/AIDS and sexual reproductive health education. Photovoice as such could thus be an important complementary method to the more conventional methods such as interviews; something also observed by Jurowski and Paul-Ward (2007).

In some subject areas including physical health, the results of the Photovoice method matched the WHOQOL-BREF assessment as shown in Table 4. Current literature focusing on evaluation research (Grandisson et al., 2014; Madden et al., 2015) advocate for a mixed- method approach in CBR evaluative frameworks. Integrating Photovoice method and WHOQOL-BREF assessment is one such approach that helps researchers to understand and embrace the diversity in disability through interpreting life experiences and quality of life.

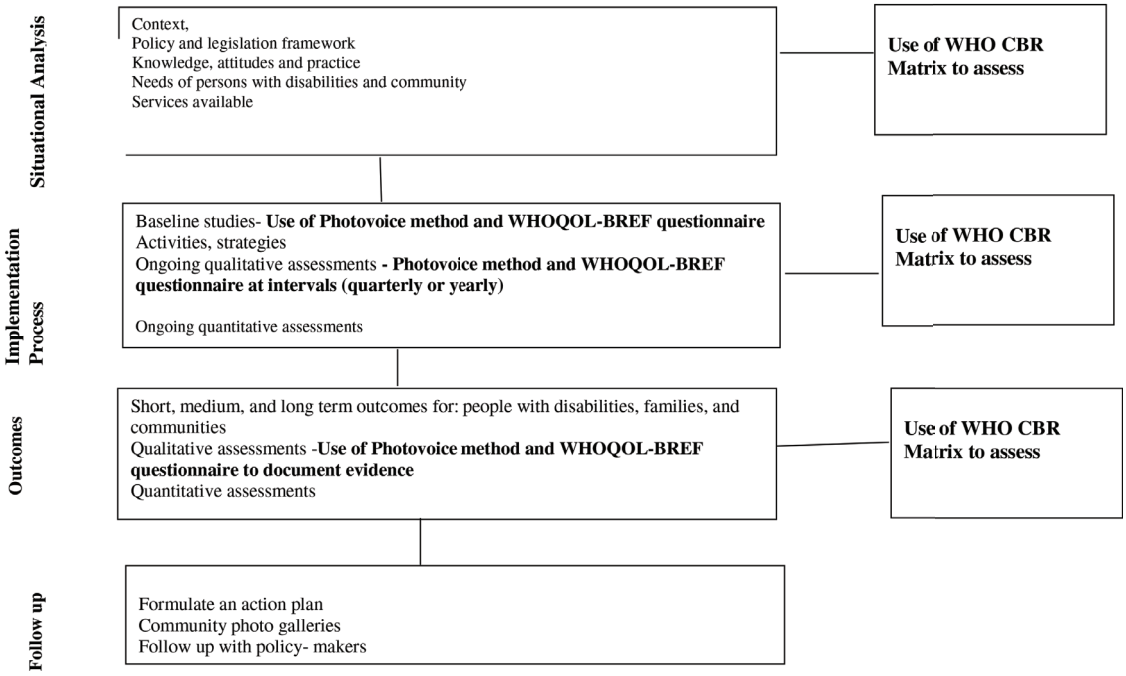
Implications

Based on the findings of this study, the following implications for practice are observed:

- Photovoice can help alleviate the challenges of research in areas with low literacy rates, which may be the case when doing research among persons with disabilities.
- Photovoice with the suggested modifications (see figure 1, Appendix II) allows persons with disabilities to reveal hidden but pertinent realities that are easily missed when using traditional data collection methods. Such realities are important for the person with a disability but may all too soon be disregarded by family members. This may, for instance, be the case when studying social and sexual relationships.
- The WHO CBR Matrix can be used as a framework underpinning CBR evaluation. Thomas (2011) and Grandisson et al (2014) proposed that the WHO CBR Matrix can be an important framework to be incorporated in CBR evaluations.
- The WHOQOL-BREF assessment tool can be utilised to generate information about quality of life of persons with disabilities but may be ineffective for persons with limited literacy levels unless support is provided from an interviewer who can explain questions that are not well-understood.
- When a review of the WHO CBR Guidelines takes place, more attention should be given to the realities of specific cultures and the issues around sexual reproductive health faced by persons with disabilities.

It is noteworthy that the WHO CBR Matrix and WHOQOL-BREF were integrated in analysing the results of this study to provide better insight into both the CBR experiences and quality of life of persons with disabilities in the two villages. To this end, this study proposes a practice framework (see Figure 2) for CBR programme evaluation in Namibia that integrates the WHO CBR Matrix, Photovoice method, WHOQOL-BREF and highlights from the other frameworks. Further research is required to validate the framework.

Figure 2: Proposed practice framework for CBR evaluation.



Limitations

The small sample size limits generalisability of the research findings. However, the results obtained are in-depth and possibly can be replicated. A large sample size is needed to confirm the findings of this study, especially with the WHOQOL-BREF assessment.

CONCLUSION

Integration of Photovoice with the WHOQOL-BREF needs to be more widely assessed as an additional tool for monitoring and evaluation of the CBR programme. The integration of Photovoice with the WHOQOL-BREF assessment can be conducted at initiation of CBR and as part of a longitudinal study to determine changes in lived experiences and quality of life of persons with disabilities. Further research is required to validate the proposed framework (Figure 2) for CBR programme evaluation in Namibia: a framework which integrates the WHO CBR Matrix, Photovoice method, WHOQOL-BREF and highlights from the other frameworks.

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