

PHOTOVOICE AS AN EFFICIENT ONLINE METHOD OF PARTICIPATIVE RESEARCH

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Abstract. Osteogenesis Imperfecta (OI) is a rare bone disease associated with a short stature and bone deformities, leading to a significant reduction in mobility. The community was asked via a participatory method presented in this article to get more insight into the mobility challenges of people with OI in everyday life. For this project, the qualitative method Photovoice was modified to a pure online methodology to reach a geographically widespread community. Based on the original photovoice method, six phases were defined in this project (Planning and Preparation, Training of practitioners as multipliers, Field phase, Group discussion, Data Analysis and Evaluation) and adapted together with PAO, students of the Master degree programme in Health, Tourism & Sport Management at the University of Applied Sciences FH Joanneum as well as peer ambassadors from the community. A funnel system (homepage, online survey, social media channels, cloud systems and online call platforms) was developed and adapted in a dynamic process during the field phase regarding the target group's needs. In Summary, four open group discussions -Kick-Off, Live Event, Final Event & Focus group- were carried out to discuss the phrase "mobility challenges", the commonalities in the Community, the received pictures and potential solutions. The evaluation showed that 286 people from the USA and Europe were reached with 83 social media (SM) posts (Facebook and Instagram) posts. Qualitatively, three points were listed that relate to the involvement of the peer ambassadors, their role in the project and the duration of the field phase (at least six months). As limitations, the missing financial support, the lack of trust in the scientific process and the missing discussion regarding each post on SM were mentioned. This form of participatory research has a high potential to reach a broader target group and create awareness.

Keywords: Participative research, Photovoice, Rare Disease,

1 INTRODUCTION

A rare disease is defined by its prevalence of less than 5 in 10,000 people. In total, over 5000 rare diseases exist, affecting approximately 6-8% of persons living in the EU. [1] One of these disorders is osteogenesis imperfecta (OI), colloquially described as "brittle bone disease", a rare skeletal dysplasia with an incidence of approximately one person in 15-20,000. The characteristic of this disorder is the fragility of the bones with a high frequency of fractures, a short stature, bone deformities, and loss of joints [2]. People living with OI experience challenges in everyday living in different domains (e.g. Chronic Pain, Fatigue, Emotional well-being, social functioning, and participation). [3] The presented study aimed to explore the mobility challenges of people living with OI. It was essential to consider that the particular community is a large, geographically widespread community with different languages and socio-economic statuses. Against this background, Photovoice was used, a visual method that aims to create a dialogue between individuals, the community, and decision-makers. The methodology keeps socio-economic and language barriers low. [4] The process of developing photovoice Online for a geographically widespread group of people with a rare disease is explained in this article. The Ethics Committee approved the project of the University of Graz (GZ. 39/60/63 ex 2020/21).

2 METHOD

A narrative literature review showed that there is still a small literature body on Photovoice Online in 2021. [5–9]. Based on the literature found and the characteristics of the community, the original methodology was modified into an online-only method with appropriate changes in the details of the methodology process and the use of adequate Online Tools.

2.1 PLANNING AND PREPARATION

The project was adapted under the label #Rarebonemobility, and the first task was to set the key aspects (Language level, questions, content/posts, etc.). Therefore, a funnel system with a landing page with all the necessary information was designed. An E-Mail (rarebonemobility@gmail.com) and SM channels- Facebook (FB) & Instagram (IG)- accounts were created, and an online Survey at Limesurvey was set to collect the data. The funnel system was promoted mainly with the corresponding FB groups of the patient organisations (PAO). This also ensured access to the target group, as ~10,000 people had already joined the relevant FB groups of the PAO. The informed consent and the survey were translated into seven languages (English, German, Italian, Portuguese, Spanish, Croatian and France).

2.2 TRAINING OF PRACTITIONERS AS MULTIPLIERS

Peer ambassadors were recruited from the PAO out of the community and received a short (1 hour) introduction to the background of the project and their role within it. Their task was

mainly to act as role models and communication interfaces to and for the target group. In addition, these ambassadors were invited to all meetings to help shape the Survey, information material, SM posts and upcoming steps from the perspective of people living with OI.

2.3 FIELDWORK

The Survey for the field phase at #rarebonemobility were discussed and adopted in an iterative process with peer ambassadors. In addition to the main questions, participants were asked to rate the individual challenges as I (big challenge), II, or III (low challenge). A Manual on how to take part was developed as a step-by-step guide, and a video about taking photos and uploading the images was created and presented Online. The field phase started with an initial group discussion as a kick-off and with the distribution of the step-by-step guide via the SM channels. Three posts and one Story (short news in the form of a video or image only available for 24h) per week were made for the first two months; in the third month, the frequency was increased to four posts/month. All partners, especially the PAO and the peer ambassadors, were asked to check the texts for the correct framing, select the images in a patient-compliant way, and whether the texts for the videos were checked for a low language level. This phase also included a deliberate search in SM channels for people living with OI who were highly active in their SM accounts. These people were actively contacted about whether they would like to participate and whether they would like to carry our project further. FAQs were summarised and disseminated both on the homepage and via posts. Individuals who submitted images were contacted personally and were asked about the story behind the pictures with the SHOWED technique, which was generally used in Photovoice projects - what they saw there, what was happening there, how does the content relate to their life, what else they had experienced and what should be done to overcome the challenges [4]. Due to language and technical barriers (data volume, internet connection, tariff costs, etc.), these questions were conducted in writing (chat or email) in the formula of a narrative interview. At the end of this phase, a voucher for € 100 was raffled off between all participants and all photos received were presented in a final video on the SM channels.

2.4 GROUP DISCUSSIONS

Three Online discussions (kick-off, Live Event, and Final Event) were organised to create an initial understanding of the topic, discuss the received images, be accessible to the community and answer various questions. Furthermore, the weekly posts aimed to generate a broad discussion with the community using the comment function of the SM platforms.

2.5 ANALYSIS OF THE RESULTS

In a final structured focus group, the images received were pre-sorted and discussed in an online format regarding the interpretation of the images, missing content and suggested solutions. For this purpose, all participants were invited to this group discussion.

2.6 EVALUATION

For Photovoice, the evaluation deals with three questions: Were the objectives achieved, how satisfied are the people involved, and what is the impact of the project on living environments, politics and other domains [4]. A quantitative (Chapter 3.1) and a qualitative (Chapter 3.2) evaluation were carried out for the #rarebonemobility project to answer the given questions.

3 EVALUATION OF THE SM CAMPAIGN

In general, it should be noted that the feedback from the community during the field phase was implemented. As a result, the homepage was adjusted twice (especially the language and the images used) in the first month of the field phase. In the last month, the community asked for the possibility of sending the photos and the signed informed consent by e-mail.

3.1 QUANTITATIVE EVALUATION

The total number of followers was 157 on IG and 129 on FB. The highest reach of the target group was 651 on FB and 386 on IG. In summary, the followers on the SM accounts were 72 % female and 28 % male. The age groups ranged from 18 to 65+ years. The age group between 35-and 44 years was most frequently involved. In total, ten countries – Norway (20.2%), United Kingdom (8.4%), Denmark (7.6%), Italy (6.7%), Portugal (5.9%), Belgium (5%), Sweden (5%), Austria (4.2%), Netherlands (3.4%), Russia (3.4%) - were listed as the most frequent countries on FB and five on IG (IG)- United Kingdom (9.6%), USA (8.9%), Austria (8.9%), Portugal (5.1%), Germany (4.5%). A total of 83 posts (47 IG & 36 FB) were posted with an average of 5.5 likes per post (8.4 IG & 2.6 FB) and, in summary, six comments (1 FB & 5 IG).

3.2 LESSONS LEARNED

The peer ambassadors often struggled to identify themselves with the project, and their level of commitment varied. It is advisable to acquire enough ambassadors for future projects and organise a structured workshop with a predefined role as a community researcher and basic methodological knowledge. It was often difficult for the steering group to find a standard solution for different cultural and linguistic behaviours. As a second point, care should be taken to ensure that the peer ambassadors, in particular, are given the resources to adapt the methods used (Interviews & Focusgroup guides) to the specific region. The third point to be addressed is the duration of the field phase, which in the project described was three months. During this time, it was impossible to handle all the target group's needs. For correspondingly high-quality output, a six-month field phase is recommended.

4 LIMITATIONS OF THE SM CAMPAIGN

It was planned to discuss the different topics of the posts with the community. Unfortunately, the posts were not commented on, and questions were only sent by e-mail or social-media

messengers. Other limitations were the infrastructural conditions of people from regions with a poor internet connection or who did not have an appropriate internet tariff to participate in online discussions.

5 CONCLUSION

The results show that Photovoice Online can already deliver good results without funding. This form of participatory research has a high potential to reach a broader target group and create meaningful results. By integrating the community into the process, it was possible to react to problems in an agile manner and thus steer the entire process towards people living with OI. The following implementation should focus on effortless communication, peer ambassadors' high involvement, including a qualification profile, and a professional supported SM campaign.

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