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Are you afraid of press and social media? Ethics in photovoice in participatory health research

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ABSTRACT

Participatory health research (PHR) and the use of arts-based methods continues to grow in popularity. Many scholars acknowledge the importance of (visual) ethics, especially in the dissemination of photographs in a digital age, but ethical issues that arise in relation to contact with the press and social media are not well documented. This article presents second-person action research of a critical case of photovoice in which ethical issues arose when a newspaper report reinforced stigma and was widely disseminated via social media. Press and social media can rapidly engage people for social change, but this also presents risks. What is the potential to stigmatize in such situations? The context of the case in this article is the participatory KLIK project, a Dutch initiative which aims to improve the health and resilience of school children aged 8–11 years in a deprived neighbourhood. Awareness of the possibility of political listening and viewing is fundamental for an ethical practice. This article shows the importance of co-ownership, media literacy and collaborative learning about ethics in PHR.

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KEYWORDS

Participatory action research; visual ethics; press; social media; political listening; community-based research

Introduction

Participatory visual methods are extending their base and growing in popularity (Mitchell, De Lange, and Moletsane 2017), and one of the most popular methods is photovoice (Wang and Burris 1997). Photovoice is gaining ground in diverse fields and disciplines (Catalani and Minkler 2010; Christensen 2019; Dassah, Aldersey, and Norman 2017; Hergenrather et al. 2009; Lal, Jarus, and Suto 2012; Yanos et al. 2015). In photovoice, people can identify, represent, and enhance the strength of their community through a specific photographic technique (Wang and Burris 1997). Participatory visual methods also provide generative possibilities for engaging participants in researching and presenting their issues through visual methods (Mitchell, De Lange, and Moletsane 2017).

A prime motive for conducting participatory health research (ICPHR, 2013a) is social change, which may include, among others, transformational learning at an individual, organizational, and community level. This knowledge may foster individual and collective empowerment, help with network building, deepen and extend relationships, and broaden people's social networks (Abma et al. 2019). Visual methodologies and creativity

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are essential for social action, and can encourage new conversations and dialogue, alter the perspectives of participants to take action, stimulate policy debates, and lead to policy development (Mitchell, De Lange, and Moletsane 2017).

Social change rarely comes without a struggle or ethical issues (Davis and Vaughan 2019), and these are at the heart of every participatory study (Banks, Armstrong, and Carter et al. 2013; Banks and Brydon-Miller. 2019; Groot, 2021.; Kwan and Walsh 2018; Sandlin, Quiroga, and Hammerand 2018; Wilson, Kenny, and Dickson-Swift 2018). Working with visual material, such as photographs taken by participants in participatory health research, raises specific ethical issues, especially when the press and online (social) media are involved. In the literature on visual ethics, the main discussion is about potentially causing harm to research participants because they are misunderstood or misrepresented, or their confidentiality and privacy are threatened (Aldridge 2012; Dockett and Perry 2007; Murray and Nash 2017; Warr et al. 2016). Harm seems to occur mainly at the point of dissemination. In addition, Warr and colleagues (2016) call attention to the ease with which digital images can be replicated and shared in an online era. While audience reception of disseminated photographs is seen as necessary (Wiles et al. 2008) in learning, engaging audiences, and social change, little attention has been devoted to ethical issues in the literature (Mitchell, De Lange, and Moletsane 2017). It seems that only a few scholars (Allen 2015; Walsh et al. 2008) have described their ethical dilemmas about photovoice and contact with journalists.

This article presents second-person action research of a critical moment in participatory health research in the Netherlands, in which the participatory visual method of photovoice was used at the start of a participatory action project with primary school children (Abma and Schrijver 2020a, 2020b; Abma, Lips, and Schrijver 2020). This study is called KLIK (in Dutch: Kinderen Leren Inventief Kracht), which refers to the click (in Dutch) of the camera and is an acronym for Children Learn Inventive Power. In this case, ethical issues arose when the Dutch press framed the project with a stereotypical message, and the article was widely disseminated online via social media. The questions this study addresses are fourfold: 1) what impact does an interview with a journalist have? 2) what values are at stake in photovoice and contact with the press and social media? 3) how did the audience receive the on- and offline disseminated photographs and messages about the project? And 4) what was the potential to represent the people and their issues in the neighbourhood in a just way in this case?

The main purpose of this article is to share lessons learned about contact with the press and related social media in a photovoice study. We focus on and explore how photovoice and visual methods can be a way to counter stigmatizing images. News and social media can rapidly engage a broader coalition for social change; however, we also acknowledge the risk of reinforcing stigmas and negative influences on trust and dignity. Awareness of the possibility of 'political listening' (Mitchell, De Lange, and Moletsane 2017) and 'political viewing' is fundamental in ethical practice, as well as using the potential to de-stigmatize.

Material and methods

Context

We assume that a way to learn about audience reception and exploration of ethical issues is through delving into the particulars of a specific situation (Nussbaum 2001; Ashcroft

et al. 2005). Moral issues are always grounded in practice, and learning starts with reflecting together on a particular situation. In this article, we delve into a case that occurred in the first year of the KLIK study, a project which lasted for four years and had nearly finished at the time of this publication. We have described the broad context of KLIK, the participatory approach, and lessons from participatory health research and photovoice in a primary school context in a previous article (Abma and Schrijver,

Table 1. Research methods, data sources and period of data creation.

Perspective	Method	Data
Participatory researchers	Second-person inquiry sessions	Conversations about experiences and reflections
	Reflections of the participatory researchers during the process	Texts in the field notes and emails between the authors
Children	Informal interviews (n = 3)	Transcribed audio-taped with participatory researchers of KLIK
	Group discussion (organized) at lecture about ethics and participatory research (1 session, n = 7)	Field notes of the plenary discussion with advocates of children
Parents	Informal conversations with the children	Texts in field notes of the second and third author
	Group discussion (organized) (n = 5) with representatives of mothers in a vulnerable situation	Transcribed audio-taped group discussion
School	Informal conversations with the parents	Texts in field notes of the second and third author
	Informal conversations and emails with the school director	Texts in field notes of the second and third author
Funder	Informal interviews (n = 1) with a representative of the charity fund	Transcribed audio-taped informal interview
Citizens	Netnography	Online (social) media posts, comments, and reaction buttons on the newspaper article
Professionals	Netnography	Online (social) media posts, comments to posts, and reaction buttons on the newspaper article
(Potential) Policymakers	Group discussion (organized) at lectures about ethics and participatory research (2 sessions, n = 80 in total)	Field notes of the plenary discussion

2020a), and [Table 1](#) in that article provides an overview of the activities in the first year, just before the newspaper article was published.

Research team

The author-team works from a critical paradigm (Groot and Abma, 2018). The first author conducted this study as a critical friend (cf. Kember et al. 1997) – a person who understands the research project, shares concerns, wants to provide honest feedback in several stages of the research process, and reflects together on the process of participatory research. The second and third authors are initiators and participatory researchers of the KLIK project. The first author had no formal connection with KLIK. She took the lead in data generation, organizing collaborative analysis sessions with the other co-authors, and sharing findings from the evaluation. She also sought to enhance mutual understanding among the three members of the author-team.

Choice of the case example

This study focuses on a critical case example that is deliberately selected as an illustrative case with ‘learning potential’. This means that even though a case is not representative, it will bring a better understanding of the activities and relationships (Abma and Stake 2001, 2014). A critical illustrative case with learning potential helps to illustrate matters that are overlooked in typical cases (Stake 1995). In practice, it was immediately apparent that this case stood out and was thought-provoking, revealing complexity, ethical issues, and social dynamics. The authors recognized the salient ethical issues this case highlighted (Banks and Brydon-Miller 2019). They felt an urgent need to reflect on what had happened in order to learn from it, to develop appropriate responses, as well as to enrich the knowledge base in the participatory action research (PAR) community (Lennette et al. 2019) and participatory visual methodologies (Mitchell, De Lange, and Moletsane 2017). Several discussions in meetings of the International Community of Participatory Health Research (ICPHR) in 2017 and 2018 further informed the decision to examine this case in greater depth, because international colleagues recognized it as an extreme case with learning potential for both ethics and participatory visual methodology.

Methodology

This article describes second-person action research of a critical case example, complemented by feedback from internal and external stakeholders. In academic research, we are used to third-person inquiry where the researcher typically stands outside the field of study. The researcher is not a neutral bystander, however. In anthropology, it is more common to reflect on the researcher as first-person, because the individual cannot be completely denied and erased from the research. In the fields of PAR and related fields, second-person inquiry is a common way to explore and reflect jointly on the researchers’ position and frameworks, and how these influence the study (Brydon-Miller and Coghlan 2018; Coghlan 2019; Reason and Torbert 2001).

Second-person inquiry is grounded in a relational epistemology. 'The experience of the relationship between persons, the act of encountering each other, is a vital and informing part of human life that is an inextricable part of how the world is understood and how knowledge of it is generated' (Coghlan and Brydon-Miller 2014, 698). In second-person inquiry researchers learn in collaboration with others in a community. By sharing experiences and feelings, reflexive thoughts, exploring issues together, listening to, and engaging other perspectives in this process, people collaboratively make sense of their experiences. Such joint and participatory reflections can be the basis of new collective actions. In this case, an academic researcher (TA) and community-partner (JS) who initiated KLIK in their neighbourhood were interested in exploring their moral questions and vulnerabilities related to their critical case example. They invited a critical friend (BG) to join them in this inquiry and ask critical questions to co-design appropriate participatory actions in response to the newspaper article.

Data collection and analysis

During the period of this second-person inquiry, the author-team examined this case by collaboratively reflecting on the situation ourselves. We also gathered data from different perspectives on the situation. The reflections from different perspectives (children, parents, school, funder, citizens, professionals, and policy-makers) informed the actions taken in the study's approach. Methods to gather perspectives of various stakeholders were desk research, netnography, informal group discussions, and interviews with diverse persons from several perspectives. See [Table 1](#) for the different data sources. The data were collected iteratively for over three years (2016–2018) in parallel with the KLIK project.

The focus of the research process was the authors' learning process. All three authors consented to the use of data for this publication. We did a member-check of the formal interviews and group discussions. This sub-study is incorporated in the KLIK study, which is approved by the Medical Ethics Committee (VUmc 2016.582).

Framework of analysis

The process of analysis was a cyclical and iterative process. We repeated steps and discussed our findings several times before we were satisfied with the answers to our questions. The first author conducted a thematic analysis of the data (Braun and Clarke 2006). First, to answer the question about audience reception, emic themes were identified: 'humiliation', 'confirmation', 'reinforcing', and 'make the personal political'. Second, by analysing the ethical dilemma, the ethical principles of participatory health research (ICPHR 2013b) served as a framework. The first author chose quotations from the data that most corresponded with the emic themes and ethical principles and discussed them with the third author until consensus was reached. Finally, in a group analysis session, the question about lessons learned was vital. The first author summarized these lessons and did a member check with the other two authors.

Quality

This study uses triangulation to overcome deficiency and biases (Denzin 1970). Different types of data sources were used, namely, texts and photographs from newspapers, other documents, and emoticons from public websites and social media, as well as transcriptions and notes from interviews and group sessions. Furthermore, multiple methods were used at different times and with different people. To ensure the transferability of this study, we tried to make the findings meaningful to others by describing them and their context in detail (thick description), and by explaining our choice for this in-depth case study to foster naturalistic generalization from the studied context to the context of the reader. We ensured reliability by collecting data until no new themes emerged (saturation) and analysing the data to inform further iterative data collection (Frambach, van der Vleuten and Durning, 2013). We continuously re-examined the data using insights that emerged during analysis (iterative data analysis). Finally, we were flexible and open towards the process and topic (flexible/emergent research design).

Various ethical principles were taken into consideration during this second-person inquiry: working on mutual respect, participation, active learning, making a positive change, contributing to collective action, and personal integrity (Centre for Social Justice and Community Action and National Coordinating Centre for Public Engagement 2012; Banks and Brydon-Miller, 2019). In practice, this meant that the three authors formed a partnership or team from the start of the project. Approval was obtained for the publication of all photos used in publications.



Figure 1. The crew of their own press agency.



Figure 2. The newspaper article that is crucial in the study.

Results

The critical case

One of the goals of the programme from the KLIK charitable foundation was to share knowledge with a broader audience. The foundation employed a public relations officer to develop a communication plan for the programme to disseminate the knowledge from the needs assessment phase of the projects. One of the actions was to share the findings of all the projects on its website. The public relations officer recognized KLIK as a unique project because it was a project with (not 'on') children, and some of the pictures of meals by made children were used in the funder's public relations and communications materials. A journalist from a quality national newspaper picked up on this material.

One Friday morning, the journalist called one of the KLIK participatory researchers. The researchers had just started their project and not yet discussed their press communication policy in any depth, either with the broader research team of children and parents, or with other stakeholders in KLIK. They did, however, discuss the approval of all photos used for publications with the children and parents (Abma and Schrijver 2020a, 2020b). That evening, a journalist interviewed both participatory researchers for an article to appear in the Monday morning edition of the national newspaper. At the point of the interview, both researchers felt that the journalist over-emphasized the negative aspects of the neighbourhood and the problems facing the children and families, as well as the obstacles to achieving a healthy lifestyle, and worked hard to persuade the journalist of the resilience among the children and families.

The result was an article in a respected national newspaper with a headline that stressed concerns about the neighbourhood, such as: 'Dit eten de kinderen in de Rotterdamse achterstandswijk Oud-Charlois' (in English: These are the children's meals in the disadvantaged neighbourhood of Oud-Charlois; see Figure 1). The text was more

balanced, but also included sentences like: *What if you provide a camera to kids in Oud-Charlois and ask them to take pictures of their evening meal? No vegetables ... in a neighbourhood with more snack bars than greengrocers ...* Six of the nine photographs that the third author had provided to the press were published above the article. The children were at that time still analysing their photographs and had only just started to prepare their exhibition.

Naivety in dealing with the press?

Overwhelming

From the perspective of the participatory researchers, the moment after the publication of the newspaper article was overwhelming. In particular, the speed of press relations and of the way the press framed the message stood out.

Researcher: It happened so fast. We just started our participatory health research KLIK, a project with children and parents in an urban neighbourhood, when we got a call from the office of the KLIK charitable foundation. They asked us if we could say something about the creative start of our participatory project: a process of photovoice with the children in the neighbourhood. I said, 'yes', because I was proud of the process with the children. Besides, the social impact could be a start to make a social difference. The next day, Friday, an interview took place. I somehow sensed that I had to ask the journalist to interview not only me but also my colleague who lives in the neighbourhood just like I have done for 30 years to gain a broader perspective than only my own. I selected nine photographs that were anonymous because we wanted to avoid doing any harm to the children. The nine photographs gave a nuanced set of photographs the children had taken in the photovoice project. I received the final article on Friday evening. If we agreed with the article, only factual errors could be corrected, not the storyline. When I saw the article at first, I was happy that they had selected six of the nine pictures, which gave a nuanced view (see [Figure 2](#)). But then I read the headline of the article and felt awful. This was not the message we wanted to disseminate. However, the editor-in-chief of the newspaper had decided on the headline. I was furious ... Although I worked as a photographer for a national newspaper in the past, this time I was on the other side, and was flabbergasted.

Ethical dilemma

The day after, many other national and local newspapers called the researchers, and a television station even wanted to do a story in the school playground. The researchers

Table 2. Post and reactions on online (social) media to the traditional newspaper article.

Source	Comments	Shares/retweets	Response buttons
RTL nieuws (online)	163		328
RTL nieuws (Facebook)	843	90 shares	709
Geen Stijl	99		
RTL nieuws (Twitter)	24	7 retweets	5
Babyenkind.nl	5		
Foodlog	2		1
Kekmama.nl			5
Facebook (Healthy living)	4	2 shares	11
Facebook (Institute for care of young children)			6
Twitter	10	22 retweets	15
Total	1150	121	1080

faced a dilemma: Should we stop or continue the media exposure? In deciding what to do, several arguments were discussed.

There were many arguments for halting the exposure, mainly because the values of shared ownership and dignity were at stake. First of all, the media attention was not anticipated and had not been discussed with the school, parents, children, and neighbourhood partners in advance. It appeared difficult to control because the journalist and newspaper determined the framing of the story (although slight changes were made). Second, the photos were not initially intended for external use, nor selected to be used externally (outside the school). The intended use was to start conversations among children, parents, and teachers inside the school, and eventually with other people in the locality. We had not yet finished with our joint process. Now the photos had suddenly been shown to a different audience and with a different purpose. Third, the names of the school and neighbourhood were in the newspaper, apparently to give credit to the school, but those involved were not anonymized, making them 'traceable' and therefore more vulnerable. Fourth, the school was vulnerable because of the extra attention attracted from external accountability institutions. Fifth, relationships that had been built very carefully over a year now came under pressure; children were always very enthusiastic, but in the article, they were now poorly portrayed. Finally, the words 'poor' and 'disadvantaged' again stereotyped and 'blamed' the neighbourhood residents. Oud-Charlois Rotterdam Zuid, a neighbourhood where dock workers used to live, had already for many years been subjected to stigmatizing representations of poverty and people with a migrant background in the mass media.

On the other hand, in participatory health research, social change and action is a core principle, and this article attracted a lot of attention, engagement, and dialogue. Exposing the project externally was a way to get public attention. It put the issues of overweight, health disparities, junk food, and 'no one taking responsibility' on the political agenda. The researchers did not want to silence real problems and health disparities. Furthermore, outsiders from academia and political movements reacted positively to the newspaper article in personal interactions with the project facilitators.

Although it was not an easy decision for the research team, they decided to stop contact with all press outlets. Shared ownership and dignity were more important than dialogue about social change in this stage of the project. The negative impact of the newspaper article on the people who are subject to the research was not a good start for this long-term project, in the view of the research team.

Researcher: I felt there was a sense of voyeurism. As a result of the chosen frame, the issue was projected on the adults [parents and teachers]. This was not good. Health disparities are not only an individual, but a social and political issue related to structural disadvantages, and this was not the frame of the newspaper article.

Social media: reinforcing stigma

By sharing lessons about this event, we, as the author-team, learned about the ethical issues and values it posed, but we were also interested in the perspectives of other stakeholders in this case. In seeking different perspectives, we found a 'hidden' online reality of which the participatory researchers were not aware. The text of the newspaper

article was duplicated in other different popular online media platforms and online newspapers, including another title: *'Kinderen in achterstandswijken fotograferen hun eten: 'Hier valt winst te behalen''* (in English: 'Children from disadvantaged neighbourhoods photograph their food: benefits can be achieved here'). Some included only one of the six photographs from the original newspaper article. These online messages were disseminated on the same day by ten different (social) media platforms. The number of reactions to the text and response buttons (likes, dislikes, etc.) from the readers is shown in Table 2. The number of passive (social) media viewers is unknown.

The analysis of the posts and reactions online and others' reactions showed that some stakeholders focused on the feelings of humiliation, but others confirmed and reinforced the stigma. Only a few more critical responses were focused on the need for social change and action, as the participatory researchers had intended. Below we describe our analysis in greater depth.

Parents and children: humiliation

People who live in similar situations as those involved in KLIK, such as the representatives of mothers and children, reacted with shock to the newspaper article. They felt that the press attention was humiliating for 'mothers like us', 'children in that neighbourhood', and the 'citizens of the neighbourhood' – the article headline in particular exasperated this audience. Although the diversity of photographs did not in any way support that message, the headline nevertheless irritated them. Most mothers and children did not read the article anyway, but especially expressed their annoyance with the way newspapers seek attention.

A mother: Humiliating. Really. It feels denigrating. I am mad about a journalist who is responsible for this.

Anonymous post 104: I do not know who wrote this item, but I am very angry. First of all, Oud-Charlois is no 'disadvantaged' neighbourhood. Just because migrants are living here? Besides ...

A child: Why this heading ... Disadvantaged neighbourhood. Why?

'Others': confirmation

A large group of online social media users expressed their opinion in short statements, repeating the message as framed by the journalist. Their posts confirmed that people in this neighbourhood were unhealthy, that parents do not provide proper meals for their children, and that 'these people' do not spend their money wisely. They gave each other examples online to support their opinion.

Anonymous post 43: I do not think it [eating unhealthily] is about money, but laziness.

Anonymous post 92: I see several examples in my neighbourhood. Daddy drinks beer, but kids need to eat rice, rice, and rice. No variety at all. But ... they have money for smoking and alcohol.

Anonymous post 275: Did you expect anything different from Charlois?

(Future) Policy-makers: some reinforcing

Some policy-makers reacted in the same way as the children and mothers. Others, and most students (future health policy-makers), responded in a very neutral way to the newspaper article. They were neither impressed nor provoked by the headline of the news item and received the message as a fact. They reinforced the headline with references to the numbers from quantitative research about deprived areas and people with a low social, economic status who have weight problems. As a reaction to a statement that mothers and children felt humiliated by the headline, this readership did not react at all. Most students did not see any ethical issues arising from this newspaper article.

A student: This is just how it is: families with lower health status do live in these neighbourhoods. Why can't we say that?

Critical audience: make the personal political

A small online audience reacted to the article in a political way. They called for attention to be paid to inequalities caused by the system. One person, for example, claimed that healthy products in the supermarket are much more expensive than the unhealthy ones, asking why healthy food is not subsidized. Others described, sometimes in detail, that if you live with difficulties, it is difficult to be creative and manage a small budget. They explained, for example, the health impact of psychiatric problems, being a single mother, working late hours for jobs that pay poorly, or always living in a state of survival. They claimed that it is easy to judge families living in a vulnerable situation, but that we as a country could organize our society in such a way that everybody can cook healthy food and be at home at dinnertime to raise their children. Some call for social action in their online reactions.

Anonymous post 166: I am a single mum and try to cook healthily, but it is very difficult. You have to look for it all the time. I think it is very bad that unhealthy is cheaper than healthy food!

Anonymous post 83: I worked as a teacher. A student of mine lived in a single-parent family. The mother worked 13 hours a day in a factory. Cooking healthily, helping your son or daughter with homework, etc. It may look cheap for businesses to exploit employees, but we pay the consequences in society as a whole.

Online reaction 21: Let's help these people and raise attention to give support to these people. Whatever type of support they need.

Online reaction 39: Stop this 'old' news. Just act!

Potential for de-stigmatizing

As the author-team, we learned from these online reactions. First of all, although newspaper attention to a participatory research project could encourage recognition of social problems and potential solutions, it could also stigmatize and cause negative feelings in the community and the stakeholders involved. The team of participatory researchers was not aware of the 'hidden' online world, in which other realities could be formed in a short



Figure 3. Reading their own newspaper together (I).



Figure 4. Reading their own newspaper together (II).

period. Second, the experience of dealing with the press is a sensitive one. In this study, the children were still in the middle of analysis and organizing an exhibition. What was their message at that moment? Their 'voice' had not yet been fully formed by themselves ready to be shared with the outside world. Finally, we learned a lot about editing and the importance of a newspaper editor-in-chief and the editorial team. Who is in the lead in making the choice regarding the final version of the text and visuals? These lessons

became prominent in the next step of the photovoice project, in which de-stigmatizing gained a significant focus.

Control of voice by starting own press agency

The research team changed their way of working by producing their own newspaper with the children and teachers and starting their own news agency (See [Figure 1](#)). Over the years, three newspapers have been made and distributed among two primary schools in the neighbourhood. The participating children first made a KLIK newspaper that showed the fun of cooking and learning about food, the advantages of the participatory methodology and photovoice, and the children's actions after photographing their food.

Researcher: In retrospect, I am so happy that we found a way to turn around this black chapter in the project. And made something fun from this incident. We found a way to represent the people of the project by themselves with art, by text, photographs, and drawing. In a way the children felt proud of —a creative and funny way, which gives energy to all of us.

The children created and wrote their news items and were facilitated by the KLIK researchers. They also joined in the selection process, choosing pictures and drawings they wanted to share, as well as the selection of, for instance, recipes with fruit and vegetables they wanted to share with other children and parents ([Figures 3–4](#)).

In the framing of the photographs and texts, the researchers were aware of the anti-stigmatization and empowerment of the children and schools. So, for example, negative images of the neighbourhood (dirt, trash, faeces, etc. – see [Abma, Lips and Schrijver 2020, 6](#)) were not censored, but went through along with funny titles the children had given them. With the newspaper, the control over framing remained in the hands of the children, teachers, and researchers. It was the start of an annual newspaper in the KLIK project. The newspapers were presented at a public meeting for all the stakeholders in the neighbourhood at the end of each school year. The children were very proud of their newspapers, and their own content, and experienced co-ownership.

Media literacy

Having learned from this case, the researchers included lessons to increase children's media literacy. Especially when they made the newspapers, the researchers discussed the photos and texts with them ([Abma and Schrijver 2020b](#)). Interestingly, for the children, the national newspaper was not that important – but their own newspaper was! They distributed this newspaper in their networks, and this was very important for them. The children grew in literacy and the way they wanted to present themselves. The first year they used acronyms for their names and chose anonymous photographs. The years after, they consciously chose how they wanted to present themselves; to shine in full glory or hide their identity. This was an effect of all the conversations the research team and the children had held, and also, of course, due to their age (being aware of others). The most important lessons were the value of freedom of choice about how and what they wanted to show.

Furthermore, the researchers became aware of the complexity of online publicity of participatory research projects. The charitable foundation also learned from this case. To

reduce any further harm towards the families in vulnerable situations in the other 47 projects they funded, the charitable foundation organized workshops on 'press relations' for all project leaders. This example was an illustrative case in the workshops.

Officer of the charitable foundation: We, among others, did not realize the impact of the article and photographs. We did not know that journalists could frame a message totally differently from the intentions of the people involved. This is counterproductive for the social and political goal of our charitable foundation to improve situations of vulnerable families.

Dignity and integrity

The critical incident was a wake-up call for the participatory researchers regarding shared ownership and the dignity of the stories and pictures. After the incident, the partnership developed further, in which the values of dignity and integrity were more crucial than before. Sharing control and discussing essential choices, like dealing with the press, were more critical than ever, and negotiations with children about the ownership of their photos and other material remained an issue during the whole project; this made the children more aware of their power and alert to their misuse (Abma and Schrijver 2020b).

Discussion

This article presents a case example of the first phase of a participatory health project. Fundamental in this first phase were photovoice and photographs. This study shows that contact with newspaper journalists, who nowadays work with offline and social media platforms, can raise ethical issues in participatory research and unintentionally harm those who are subjects of the study, as documented in the study reported by Walsh and colleagues (2008). Our study corroborates these findings and adds the extra dimension of the online (social) media related to press agencies. The speed, the size of the audience, and the possibility of getting reactions from a broad audience is compelling and calls for attention, especially with photographs, which are new material for an audience in today's visual culture. The involvement of the press and online social media adds an extra layer of complexity because, in such processes, the media is difficult to control (Wiles et al. 2008). It is a 'double-edged sword': it could set the agenda for topics, but it could also lead to 'unintentional harm because access to social media is beyond a researcher's control and the impact of dissemination is hard to trace' (Yang 2015, 361).

The reception of a message in visual and text, framed by the selection of the press (Bock 2020) and disseminated online, could differ, as we also see in this study. Online (social) media can play an essential role in supporting and reconfirming images (words and visuals related to 'unfortunate' and 'underprivileged'). Re-stigmatization of people and place (Kwan and Walsh 2018) and the so-called 'place-based stigma' (Byrne, Elliott, and Williams 2016; Goffman 1968) are even more likely to occur with this online dimension. Whether or not they are accurate, such images have an impact on those living in these areas. People may internalize these images, which can cause feelings of shame and disgust. Stigmatized photos can be easily reinforced by social media users and (future) policy-makers and, conversely, insult those living in a marginalized position. The value of 'dignity' (ICPHR (International Collaboration Participatory Health Research) 2013b), which is a central ethical principle in participatory research, is currently under pressure, and

participatory researchers need to do ethics work, such as framing work (Abma 2020; Groot and Abma 2021) to be extra alert not to reproduce stereotypes that point towards individuals. At the same time, the problems are mainly caused by structural inequalities and disadvantages.

The involvement of the press and social media in photovoice can also bring a positive focus on a project and engender change. As we see in this study, it can rapidly engage a broad audience. Potentially, it can kick off dialogue on social and policy change, an important value of participatory research (ICPHR 2013a, 2013b). Contact with the press can also lead to attention being drawn to the issues of the people involved, and to their positive reaction (Allen 2015; Walsh et al. 2008). However, although some potential stakeholders react in an engaging way on- or offline, and even make the personal political, real engagement demands more. It calls for serious attention and time to feed engagement on- and offline, for example, to enhance the (online) dialogue by reacting to posts and shares, or to invest in engaging the audience as a potential partner, or to make a difference. In practice, audiences such as policy-makers tend to be alerted to research findings only at the end of the study, when they are invited, for example, to an exhibition of visual materials (Mitchell, De Lange, and Moletsane 2017).

Moreover, the complexity of power-sharing is broadly discussed in the literature on participatory health research (Groot and Abma 2019), and this study is an illustrative example. Central to photovoice is that the photographs need to be 'seen, but not seen without us' (Holtby et al. 2015). The choice of an exhibition form in photovoice (Evans-Agnew and Rosemberg 2016) and shaping the narrative of a story that will resonate with an audience (Gubrium, Hill, and Flicker 2014), is supposed to be a participatory process (Wang and Burris 1997). If not, it could lead to public voyeurism (Holtby et al. 2015) and discomfort (Sandlin, Quiroga, and Hammerand 2018), as in this case. This study supports the need for researchers to anticipate media attention from the start of a photovoice project. Furthermore, time pressure, based on the press deadlines, can lead to choices to work in a less participatory manner under duress. At that point, the critical value of 'shared ownership' in participatory research (ICPHR 2013b) is potentially compromised.

How can we understand how this critical incident occurred? 'Political listening' (Alexandra 2015) is a helpful theoretical notion of understanding the power mechanisms of participatory knowledge production with visual methods. Although the strength of working with visuals is that you cannot look away, in practice, it is much more complicated. Political listening in the context of visual research means that you can see only what we want to see (Mitchell, De Lange, and Moletsane 2017). In this study, different audiences saw, listened to, and interpreted the message from their frame of reference, and what they wanted to see. It is a political act to see or not to see and react. Political listening also draws attention to the collaboration among participants, researchers, funding agencies, and others who all have different ideas about which stories to tell, who is best positioned to tell them, how they 'should' and 'should not' be told, and 'what is at stake' (Alexandra 2015, 43). These questions could be guiding principles in the discussion on press relations and posting on social media (Bos and Abma 2019).

Finally, this study calls for attention to bring the topic of press relations and social media in participatory (visual) research to the fore in the scholarly field and in the ethics

review board. It is often an undiscussed topic (Hays, Spiers, and Paterson 2015). Although the ICPHR (2013b) guidelines set out questions on deciding collaboratively on how to share material, the press or social media are not identified. Mitchell and colleagues (2017) identify a list of questions that could help in reflecting on which visuals will be shared with the press and social media from the Critical Visual Framework (Rose 2016, 25). An example of two questions include: Who made the visual, who for, why? (production level); How is it interpreted, by whom, why? (audience level); Who organized it, and why? (circulation level) What are the visual effects and visual meanings? (the image itself). These questions could help group discussion about what to expect and how to react and engage online. Parallel to this framework, the model for visual framing of Bock (2020) offers a three-part model for thinking about visual framing that focusses on special characteristics of visual communication; how can we *select* images that work in context with surrounding material, how can we *create* with visual conventions *within*, and how can the frame serve as a *solution* to a cognitive puzzle?

Concluding, this case shows that press coverage raises ethical challenges for all involved, especially working with people living in vulnerable situations. Journalists may frame their message regarding a photovoice or participatory health project in a way that reinforces stigma regarding people and places. Social media and affiliated online press platforms swiftly spread the word (and photographs) beyond the researcher's control, and also, in this context, politicized listening and viewing take across a broad audience. In participatory research, 'make a difference' is an important principle, but other principles, such as 'shared ownership' and 'dignity', can be an issue. An awareness of the possibility of political listening and viewing is, therefore, fundamental to ethical practice in all participatory research that uses visual methods.

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Conflicts of interest

No potential conflict of interest was reported by the author(s).

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