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van der Ham, A.J.

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CHAPTER 6

Stimulating service user involvement and user-provider dialogue through participatory video: deliberations on long-term care in a psychiatric hospital

Abstract

Recent trends in health care indicate a shift toward service user-centered care and an emphasis on dialogue between service users and providers. The aim of this study is to assess the role of video-mediated moral deliberation in stimulating dialogue between service users and providers. A participatory video project carried out in a long-term care facility of a psychiatric hospital was investigated as a case study. Data were collected through interviews, a focus group and a dialogue session with providers, service users, managers and a family member. Data analysis produced four themes: 1) the video elicits discussion by affecting viewers; 2) the video raises awareness and discussion of service users' needs and desires; 3) the video and discussion give a voice to service users; and 4) the video and discussions draw attention to user-provider relations. The study shows that video-mediated moral deliberation can be a useful tool for starting dialogue between service users and care providers. It can also contribute to changes in care provision by acting as a catalyst. This study provides an example of how video-mediated moral deliberation can be applied in the context of psychiatric care. Opportunities regarding the usefulness of video-mediated moral deliberation include training purposes and education.

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Introduction

Recent trends in Dutch health care indicate a shift toward service user-centered care and an emphasis on dialogue between service users and care providers (Casparie, 1993; Ham & Brommels, 1994). The involvement of service users in health care service planning and evaluation is thought to increase the quality, democracy and acceptability of care (Fiorino, 1990; Telford et al., 2002). Service user involvement requires interaction and communication between service users and providers. A key aspect of this dialogue is what service users and health care providers define as ‘good care’. Because definitions of ‘good care’ are formed by the experiences, values and opinions of the different stakeholders, the perspectives of the stakeholders involved have to be explored and understood in order for dialogue to be constructive and meaningful. This study assesses the use of video-mediated moral deliberations for stimulating service user-provider dialogue.

Moral deliberations about ‘good care’

Abma et al. (2009) provide insight into how to initiate and carry out the discussion of ‘good care’ in a meaningful and constructive way by conceptualizing it as a practice of ‘moral deliberation’. Moral deliberation is based on hermeneutic ethics, in which experience is regarded as the source of moral wisdom. The exchange of concrete experiences and perspectives is needed to come to a moral understanding of the issues at hand (Widdershoven et al., 2009b). Moral deliberation takes place in recurrent dialogue sessions where participating stakeholders share their experiences and notions of their practice (Walker, 1998; Widdershoven & Abma, 2003). This can result in the empowerment of stakeholders by giving them a voice and building shared understanding. It might also lead to a change of practice when people start questioning their own practices and discover opportunities for improvement. Moral deliberation initiatives predominantly focus on dialogue between health care professionals. A literature search indicated that the number of initiatives involving service users, and particularly vulnerable populations such as chronic psychiatric service users, is very limited. One example that was found, a moral deliberation project in a psychiatric hospital (Abma & Widdershoven, 2006) demonstrated that inclusion of the service users’ perspective was hindered by asymmetrical relationships between care providers and service users and requires deliberate attention. It was therefore decided not to bring them together in a face-to-face conversation, but instead they chose to describe the life world experiences of service users in the form of a story. In the study presented in this paper, participatory video was employed to enhance the direct (face-to-face) involvement of service users in discussions with care providers in a psychiatric hospital.

Storytelling through participatory video

Narrative techniques are particularly useful for the interpretation of experiences and perspectives, since they make the meaning of people's experiences explicit (MacIntyre, 1981). Storytelling is often used in service user education and communication to gain an understanding of service users' experiences of illness and care (Fix et al., 2012; Haidet et al., 2006). Video is increasingly used as a medium to capture stories in order to enrich discussions and increase comprehension and retention (Deep et al., 2010; Frosch et al., 2003). The involvement of service users in sharing their stories can be enhanced by means of participatory video (Lunch & Lunch, 2006). White (2003) explains that "Video programs should be produced with and by the people, about their social problems, themselves, and not just produced by outsiders". The process of participatory video can be empowering for marginalized groups, enabling them to communicate their needs and perspective to other groups. It has been used in different parts of the world in various contexts, such as community development, training and education, therapy, and political and social activism (White, 2003). Participation can take place at different levels; it ranges from projects in which service users take the lead or have equal control, to projects in which people provide input and advice, but in which they have little decision-making power (Haw & Hadfield, 2010). Considering its power to reveal the experiences and perspectives of its subjects, participatory video could be a useful tool in stimulating the discussion of 'good care' between service users and providers, emphasizing the service users' perspective. To date, no studies have applied participatory video in the context of moral deliberation in health care.

Objective of the study

In 2008, the participatory video project, 'At least it should have some bubbles', was carried out at a psychiatric hospital in the Netherlands. The project consisted of the making of a video representing the service users' perspective on long-term care followed by a round of moral deliberation sessions during which health care providers and service users met to watch and discuss the video. The aim of this study is to assess the role of the participatory video project in stimulating the exchange of experiences and perspectives between service users and providers using this project as a case study.

Methodology

Participatory video: "At least it should have some bubbles"

The participatory video project was carried out in a psychiatric hospital in the Netherlands, providing psychiatric care and assistance to about 10, 000 people at five different locations. The hospital offers ambulatory care, day-care and clinical care, and has long-term care facilities. In 2007, the psychiatric hospital started a project to generate new

impulses for the quality and organization of their long-term care facilities. Different stakeholders, including service users, family members, health care providers and other professionals, were involved in the project. Within the scope of this project, the video “At least it should have some bubbles” was made (see box 6.1).

Box 6.1 Description of “at least it should have some bubbles

“At least it should have some bubbles” is a video about long-term care in a psychiatric hospital in the Netherlands, made by three independent filmmaking professionals in commission of the hospital. The filmmakers deliberately chose to take the perspective of the service users to investigate the current state of care at the hospital. Often, these service users have spent a significant part of their life within the walls of one of the departments of the institution. The narrative of the hospital, its inhabitants, care workers, management and relatives emerges from the personal stories of the service users. The filmmakers adopted an appreciative inquiry approach, focusing on the ways in which these service users managed to live meaningful lives. Although the service users that told their stories did not have complete control of the filmmaking process, they were involved in several stages of the process. At the start of the project, the filmmakers discussed the intended content and focus of the video with service user representatives. The filmmakers used an open interview structure and let the themes emerge from their understanding of what the service users had to say. They continued to discuss the emerging storylines with service users regularly to ensure that the themes addressed in the video expressed the service users’ perspectives. The service users were asked for approval of the video after a pre-screening. At that moment, the involved service users and the hospital management decided together to use the video as planned in a series of discussions between care workers and service users at the hospital. The video presents the stories of 5 Dutch service users. The service users involved suffer from different psychiatric disorders, such as depression, bipolar disorder and schizophrenia. In the video, these service users tell the story of their daily lives and experiences at the institution. Themes addressed are the service users’ dreams, aspirations and life goals; the often stigmatising way in which people (also care workers) respond to psychiatric service users, the interactions with care workers in the production of care; the tension between freedom and restriction in the life at the institution; the approach to care and more. The title of the video refers to a story one service user told about his art therapy. He had a period in which the only drawings he made pictured men drowning in black oceans. The art therapist suggested at least adding some bubbles to show that these men were still alive. The service user indicated that this suggestion for him had become representative of the possibility of a meaningful live. The service users’ stories are alternated with images of the institution and a poetic voice-over representing the institution building’s voice. The building’s voice raises underlying ethical and philosophical questions, such as ‘Can I help you without making it impossible to do without me?’ Together, the service users’ stories and the poetic voice-over gently explore the tensions between autonomy of the service users, the constraints of psychiatric care and the structure of a health care organisation. The video invites the viewer to reflect on a very fundamental question in human life: what is ‘good care’?

Since 2008 the video has been presented at several locations within the institution and used as a starting point for the discussion of care issues between service users and health care providers of a particular treatment unit. At a later stage, the video was also presented to external parties, such as other psychiatric hospitals, housing companies, municipalities and politicians. During the screening of the video, a health care provider and one or more of the service users portrayed in the video were present. A similar structure was used during all presentations. All sessions started with an introduction about the psychiatric

hospital, followed by an introduction about the video by one of the service users. After the screening, a discussion was initiated by asking the people present for their first impressions of the video. The discussions were continued according to the input given. By the end of the year 2009, the video had been shown more than 80 times.

Responsive evaluation

The participatory video project was evaluated as a case study (Yin, 2003). To assess the video-mediated moral deliberation sessions that took place in this project, we used the Responsive Evaluation methodology (Stake, 1975). Responsive Evaluation is a process-oriented approach that focuses on the dialogue between stakeholders to identify criteria for assessment (Abma, 2005; Guba & Lincoln, 1989). These criteria include a wide range of issues that reflect the perspectives of different stakeholders regarding the video and subsequent discussions about ‘good care’. In our study we applied Responsive Evaluation in three phases. In total 17 persons participated in the study, including health care providers (6), service users from the long-term care department (8), family members (1) and managers (2). In the first phase all participants were interviewed to identify the issues they considered important. All stakeholders had seen the video at least once, and four of the service users had been involved in making it. In the second phase, five service users (who had also participated in the interviews) took part in a focus group to verify and elaborate the preliminary themes derived from the interviews. We paid specific attention to the issues of service users, because they were expected to have a weaker voice compared to the other stakeholder groups (Lincoln, 1993; Elberse et al., 2011). In the third phase, we aimed to stimulate interaction and dialogue between participants from different stakeholder groups in a dialogue session. The participants had all participated in the interviews and included: a manager, six service users, a family member and two health care providers. During the dialogue session, the issues that had emerged from the individual interviews and the focus group with service users were validated and adapted by stakeholders. In the different phases, member checks were done to validate the identified issues. The data were transcribed and coded following standard qualitative coding procedures (Strauss & Corbin, 1998). The assessment was an iterative process. In recurrent cycles of interpretation, expressions that were meaningful with regard to the role of the video in the discussion of ‘good care’ were identified and clustered into thematic ideas. We collected the data in July and August of 2009, approximately one year after the first screening of the video.

Ethical considerations

The service users were recruited through the head nurse of the long-term care department of the psychiatric hospital. Service users who were able and willing to participate received an invitation explaining the purpose of the research at least two weeks before the interview took place. At the beginning of each interview, focus group and dialogue session,

participants were asked to read and sign an informed consent form. It stated that participants had been informed about the purpose of the research and consented to the recording of the session. In addition, the researchers signed a privacy statement, declaring that the data would be treated with confidentiality.

Results

Data analysis revealed four themes which indicate different aspects of the role of the participatory video project in stimulating the exchange of experiences and perspectives between service users and providers: 1) the video elicits discussion by affecting viewers; 2) the video raises awareness and discussion of service users' needs and desires; 3) the video and discussion give a voice to service users; and 4) the video and discussions draw attention to service user-provider relations.

The video elicits discussion by affecting viewers

All stakeholders described the strong impact that the video has on viewers. Several of them thought that the visual presentation of the stories enhanced their impact, as illustrated by a comment from a health care provider:

Images often say more than a thousand words. It is not a coincidence that after one and a half years, I can still easily recall parts of the video. This would not have been possible if they were merely stories from service users. Images have a different impact on your memory, and that is why I think it was very powerful to see and hear the service users, only the service users.

The stakeholders indicated that the video elicited a range of emotions among its viewers, such as anger, sadness and hope. This is reflected in a comment from a manager:

The video touched me, I literally got tears in my eyes; so beautiful, so sad, at the same time. [. . .]. also the audience was silent and touched. In general, I think that this is what I see with other people; it is emotional, sad and beautiful.

Different elements from the video elicited responses from viewers and formed a starting point for discussions. Many stakeholders explained that the recognition of certain images and stories aroused emotions. For example, one service user said:

I remember the story about the number of doors, the number of windows and the number of closed doors. That did something to me, because I've been locked up too, and there were closed doors as well; I couldn't get out.

According to several stakeholders, controversial statements made by service users in the video especially caused heated discussions. A service user who appeared in the video gave an example:

At a certain point I say something about people in long-term care, that they are already dead but don't know it yet. I got many responses to that, also angry ones. [. . .]. The angry responses were like: 'we [service users, authors] are not spoiled'. Other people said: 'yes, you are actually right'.

Some stakeholders mentioned that although the initial impact of the video was profound its impact was temporary and faded within several weeks. A minority of the health care professionals and service users thought that the video did not lead to much discussion, or indicated that they were unable to recall the content of the discussion.

The video raises awareness and discussion of service users' needs and desires

According to all stakeholders, the video provided insight into the daily lives of service users and shows that they - like other people - have needs, desires and dreams. According to different stakeholders, this emphasizes the service users' strengths and possibilities over limitations and failure. For example, a health care professional said about the video and discussion afterwards:

At a certain moment it led to a conversation about dreams: Can you tell your dreams? Do you dare to tell your dreams? Are you allowed to share your dreams?

The video stimulated the discussion of prejudices about service users that are held by health care providers, service users themselves and society in general. According to these prejudices, service users are not willing to become active and unable to recover. Many stakeholders indicated that the video provides a different view on service users, which is reflected in a comment from a service user who participated in it:

The video gives an impression of people who really want to live and are willing to accept certain barriers and difficulties. [. . .]. A lot of people outside the institution have no clue about what service users do here; that all they do is drink coffee and nothing else. I think that maybe that image has been corrected a little bit.

Several stakeholders felt that by showing the needs and desires of service users, the video might contribute to reducing the stigma of mental illness. For example, a family member of a service user said:

It can be used to give people insight into what life is like for service users by creating understanding. Maybe it also helps to take away some of the stigma attached to it. That is why I am enthusiastic about this video: I think it can do that.

Several stakeholders indicated that the video stimulated health care providers to reflect on their own perceptions of service users; they started to see service users in a different way. This is illustrated by the following comment from a service user who was involved in the making of the video:

Afterward, a nurse who worked with this service user told me, 'I never thought about it that way, I always thought I already heard this story, but now I realize that what actually matters is that he can tell his story, and we only have to listen. Too bad I did not know this earlier'.

The video and discussion give a voice to service users

The video and discussions helped service users to articulate their perspectives in several ways. By including only service users in the video, the issues formulated by them provided a starting point for discussions afterwards. According to several stakeholders, the presence of service users involved in the making of the video encouraged other service users to speak up, which is reflected in a comment from a service user who participated in the video:

If I support what service users say, they feel strengthened. They will join the discussion together with me and I can bring it further and it comes across different than when [a provider] would say it.

The voicing of service users' perspectives enhanced the discussion of empowerment of service users. During some discussions, service users expressed the wish to become more involved in the organization of activities, so the activities would better suit their needs and preferences. In addition, some service users wanted to have more influence on their care plan. According to several stakeholders, the video contributed to the actual empowerment of service users. This is illustrated by the following statement from a service user:

It made me stronger. Like: 'if those people [in the video] can do this, so can I'. [. . .]. But in a decent way I will just say: 'I don't really like this'.

The service users who had been involved in the making of the video indicated that the video and discussions helped them to become more assertive. For example, one of them said:

It gave me self-confidence. Part of it is that people responded in a positive way to what I said. What I said comes from me. It is my achievement, and it makes me feel like: 'yes, I can do it'.

The video and discussions draw attention to service user-provider relations

The video addresses the way health care providers and service users interact with each other; how they treat each other, how they are involved with each other, and what they do together. According to different stakeholders, the video addressed the importance for health care providers to have an appreciative attitude toward service users, being appreciative of service users' opinions, wishes and dreams. Some health care providers indicated that the video did not change their attitude or way of working, but confirmed them in their current approach. Others indicated a change in their attitude or way of working, as illustrated by the following comment from a health care provider:

Maybe more like: "What do you want? What are your wishes?". I notice that a lot of service users are not used to this: "What do you want?". This has become clearer by asking more open questions. Service users don't always immediately know what to say, because they never said this before.

It implies giving service users a responsibility in accomplishing this. This is illustrated by a comment from a service user who had been involved in the making of the video:

What clearly shows in the video is that service users themselves are capable of determining what they want to a great extent. [. . .]. If they are challenged, they become motivated. If they do more in the institution than drinking coffee and notice that others are trying to involve them, many opportunities arise, and you might see a different side of service users.

According to different stakeholders, the video addressed the interaction and communication between providers and service users concerning the care and activity planning in the institution. Central to this discussion was that activities were often organized by health care providers, which resulted in a low commitment of service users and low attendance at the activities. Several stakeholders indicated that the fact that health care providers and service users sat together to watch and discuss the video stimulated collaboration between them. A manager described how the video provided a starting point for a discussion of this topic:

For example in the day activity centre, it was the first time that service users and providers sat together to have a discussion. The conclusion of this discussion was that you can provide better care if you work together instead of having them decide what is good for you. They did many things after this; they are building a tea garden with the neighbourhood and in collaboration with service users.

During some discussions, only health care providers and no service users from particular departments were present. According to a manager and a service user, this was symbolic for the distant relationship between providers and service users in these departments. It also provided a starting point for the conversation since the absence of service users could be discussed.

Discussion and Conclusion

Discussion

The case study of the participatory video project, 'At least it should have some bubbles', indicates that the video-mediated moral deliberation sessions helped to stimulate the discussion of 'good care' in the psychiatric hospital. The video served as a starting point for discussions between service users and health care providers. Characteristics of both the

video and the moral deliberation exercise (discussion sessions) played an important role in this process.

Participatory video

The results of our study show that the video was able to affect people and elicited a discussion among viewers. The visual representation of these stories appeared to increase the impact of the video. The stories of service users play a crucial role in bringing forward their perspective and opening up the discussion of these issues (Abma, 2005). The involvement of service users helped to ensure the authenticity and relevance of the stories, which becomes evident in the recognisability of the stories and images and their ability to evoke emotional responses. The focus on service users appears to have contributed to the empowerment of service users (Bery, 2003). It helped raising awareness of the service users' needs and desires, which caused some health care providers to change their way of thinking about service users. In addition, it showed that service users often want and are able to have more responsibility in care processes and emphasized the importance of dialogue and collaboration between service users and health care providers. Furthermore, the service users who participated in the video were strengthened through their participation.

The independent film makers played an important role in facilitating the process of making the video (White & Nair, 1999). Service users were not directly involved as the directors of the video, but the content was established with and formally approved by the service users. The collaboration between the professional film makers and service users led to a video that was acceptable for all stakeholders involved and was considered of good quality. It would be interesting to explore the potential of a participatory video project in which service users have full control over the process. On the one hand, this might further enhance the empowerment of the service users. On the other hand, this could affect the (professional) quality of the video and its ability to connect to stakeholders other than service users.

Two factors might have influenced the interpretation of the effects of the video. First, the assessment took place approximately 1.5 years after the first screening of the video. An earlier assessment might have provided more details on the immediate impact of the video and the content of the following discussion. Second, several of the study participants had been involved in the making of the video and might therefore be more positive toward it.

Moral deliberation

The participatory video facilitated the discussions that took place afterwards. The design of the discussion sessions as a practice of moral deliberation played a crucial role in further enhancing the dialogue between health care providers and service users. The discussion sessions were able to build on the video partly because similar principles were emphasized in its set-up. Similarities included focusing on service user involvement and empowerment and the interaction between service users and health care providers.

Moral deliberation aims to stimulate dialogue and understanding between the stakeholders. The interaction between health care providers and service users was an important theme in the video as well as in the discussions afterwards. The set-up of the structured discussion sessions provided a platform for people to articulate their viewpoints on this and share them with each other. The structured reflection meetings are a core aspect of moral deliberation. Usually, they are part of an ongoing dialogue, but our case study consisted of single discussion sessions. Although the video and discussion sessions initially had a profound impact on viewers, this often seemed temporary and faded within several weeks. Continuation of these single discussion sessions might further enhance the impact.

The focus on the involvement of service users distinguishes our case study from common practices of moral deliberation, since this is mostly carried out among providers (Abma et al., 2005). Our study shows that the presence of a service user advocate (service users who had been involved in the making of the video) during the discussion sessions was important because this helped service users to speak up and supported them in their views. This strengthened the service users as well as the service user advocates and appears a useful approach to dealing with asymmetrical relationships between service users and care providers. It can thereby contribute to achieving an equal balance of power among the dialogue partners, which is an important condition for moral deliberation (Abelson et al., 2003). Our study emphasizes that all relevant stakeholders should be present during the discussion, since the scope of what was discussed was very limited in discussion sessions where only providers were present.

Participatory video and moral deliberation as catalysts for change

The video and discussion sessions which were assessed in our study were part of a larger project in the institution aiming to generate new impulses concerning the quality and organization of long-term care. The larger project seemed to create an enabling environment for the video and for moral deliberation which enhanced their impact on care practices. The video in combination with the discussions served as a catalyst for change. It accelerated several changes in the institution which were already taking place; service users are discovering their own strengths and assume more responsibilities in care processes and health care providers have started to reconsider their views on service users and the way they interacted with them. As a result, service users and health care providers appear increasingly involved with each other, and they collaborate better.

Conclusion

The study shows that video-mediated moral deliberation is a useful tool for starting dialogue between service users and providers. It can also contribute to changes in care provision, mainly by acting as a catalyst. The content of the video, the type of participants and the structure of the discussion afterwards significantly determine the effects of the

participatory video. The effects of the participatory video depend on the context in which it is carried out. Therefore, the characteristics of a certain setting and the relevant stakeholders have to be carefully assessed before and during such a participatory video project. Its impact might be further enhanced by closer involvement of service users and structured ongoing discussions, but further research on the barriers to the involvement of vulnerable populations is needed.

Practice implications

This study provides a clear example of how a participatory video can be applied in the context of moral deliberation in health care service planning. The unique possibilities of this method lie in the visualization of stories from stakeholders and giving a voice to service users by articulating their perspective. Opportunities regarding the usefulness of video-mediated moral deliberation include training purposes, education of new employees, family members and external parties, and ongoing moral deliberation.