Unveiling the Unspeakable: Integrating Video Elicitation Focus Group Interviews and Participatory Video in an Action Research Project on Dementia Care Development

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Abstract

With the intention to comprehensively reflect the reality, foster interactions between researchers and participants, and empower the marginalized groups to be heard, videos are increasingly used in health studies. The findings of an action research project that integrates video-based methods into the development of dementia care in an aged care home in Hong Kong are reported. A working alliance consisted of practitioners, community-dwelling volunteers, service managers, university educators, and researchers was formed to develop a sustainable, need-based play program for the institutionalized elderly with dementia (EWD). Two innovative methods, namely, video elicitation focus group interview (VEFI) and participatory video (PV), were applied. Data analyses were collaboratively conducted by all practitioner-researchers during eight reflexive sessions. Several short films were made through PV for institutional training and community education. VEFI effectively enhanced the practitioners' understanding of the embodied expressions of the EWD and provided a reflexive, democratic environment to generate knowledge among practitioner-researchers. Counter-narratives of the EWD and educational materials on dementia care were generated through PV. The study demonstrates how innovative video-based methods may enable participatory health research to be more inclusive, engaging, and empowering, and how these methods may provide new perspectives on the ethics of researching vulnerable populations.

Keywords

video elicitation, participatory video, participatory action research, dementia care

Background

The increasing prevalence of dementia has become a major challenge to both the physical and psychological well-being of the aging population as well as their caregivers (Langa, 2015; Schulz & Martire, 2004). Dementia is a chronic condition generally associated with progressive cognitive deterioration and decline in other significant life aspects. Currently, the evaluation of the EWD is most often focused on disease and deficiency, potentially promoting a negative or even stigmatized image of dementia in the society (Algar, Woods, & Windle, 2016; Milne, 2010), leaving the diverse lived experience of dementia largely ignored (Bond & Corner, 2001; L. M. Miller, Whitlatch, & Lyons, 2016). The voices, needs, and experiences of the EWD ought to be acknowledged in intervention studies to achieve desirable outcomes (McCabe, You,

& Tatangelo, 2016; L. M. Miller et al., 2016). Partly due to the EWD's impaired cognitive functions and communicative capacity, researching the lived experience of the EWD and

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responding to the individual needs have long been a challenge in servicing this particular group (Nygård, 2006). Besides the disease-related barriers, the EWD also encounter marginalization and stigmatization in their daily lives (Benbow & Reynolds, 2000), reinforcing the difficulty and insecurity they may experience in expressing their authentic thoughts, needs, and emotions.

As results of many studies are usually not applicable or nonsustainable in the actual service settings, there is a gap between research and practice in dementia studies (Seitz et al., 2012). Most studies focus on measuring the outcomes of a standardized intervention developed outside the research context, while the microprocesses of change and practice development have seldom been documented or analyzed. Both in terms of its relevance and utility for practitioners, the absence of process research may compromise the potential of an intervention system and its own ongoing refinement in response to the changing service needs and circumstances.

Play Intervention for Dementia (PID)

PID is a practice initiative first developed in Toronto, Canada, in 2013 (K. Y. Liu, Wong, Chu, & Leung, 2018) based on the Strategies and Skills Learning and Development system (Tsang, 2013). The basic assumption is that most of the EWD have a need for activity, pleasure, interaction, and creativity, and authentic play provides them with opportunities to fulfill those needs. The program runs weekly and each play session is around 75 min. The EWD are divided into groups of four to six to participate in games that are rotated across the groups, each lasting approximately 8–10 min to maximize stimulation. The games are designed collectively by the researchers, volunteers, and staff according to the EWD's needs, circumstances, characteristics, and capacities. Creativity and spontaneity are especially encouraged, and the games generally do not conform to "normal" imagination (e.g., colorful balls may be thrown at drums to make music to promote eye–hand coordination and emotional release). Diverse instruments are used including toys, musical instruments, painting tools, and other items that the EWD can engage in.

The games vary in form and function. For example, one PID session usually includes gross motor exercises (e.g., ball throwing and kicking), fine motor exercises (jewelery making), cognitive capacity (creative poker), communicative skills (storytelling with building blocks) and, most importantly, encompasses creativity and social interactions. In this program, play is conceptualized not as an infantilizing and trivializing activity, but rather as a realm to explore how the EWD make sense of their experiences, express themselves, and build relationships (Swinnen & de Medeiros, 2017). How play unfolds depends on the elderly's involvement and expressions, and the play facilitators do not impose any rules on the participants. Instead, the facilitators pay close attention to the participants' reactions and follow their lead to create a supportive space where the elderly can play and express themselves freely.

Hong Kong has a rapidly increasing aging population, and to achieve age-friendliness within the city, there is a need for enhanced human interactions among the elderly in social services (Chui et al., in press). PID, as a person-centered, inclusive practice innovation, potentially achieves this goal among the EWD. With the purpose of contextualizing and implementing PID at a specific practice site as well as developing it into a culturally competent practice model, a PAR project integrating video-based methods was conducted at a nursing home in Hong Kong. Sociocultural contexts play an important role in dementia research (Downs, 2000), and the feasibility, effectiveness, and sustainability of an innovative practice largely depend on its compatibility with the local caring culture.

By convention, surveys, in-depth interviews, and field observations are adopted to explore the culture and practices of a specific context. However, due to both disease-related difficulties and cultural factors, verbal reports and single-perspective observations may not reveal the complexity and contingencies of a local dementia care institute. Interviews do not always accurately reflect the process of practices (Bond & Corner, 2001), consequently excluding the EWD with low communicative capacities. Coupled with the sense of guilt of being a burden and the fear toward losing their social standing, it is therefore difficult for the Chinese elderly to express their personal needs and describe their challenges associated with aging and deficiency (Mok, Lai, Wong, & Wan, 2007). Sometimes, the stigmatized image of dementia also prevents the EWD from sharing their lived experience (D. Liu, Hinton, Tran, Hinton, & Barker, 2008). Appreciating that it is not possible to draw a singular picture of the cultural conception of dementia in China, it is thus crucial to include both the practitioners and the EWD within a specific context in this exploration. Video-based methods provide rich data of both verbal and nonverbal expressions of all participants, potentially enriching the researchers' understanding of the context of their studies.

Video-based methods are especially effective in unveiling nonspoken events that may carry personal significance (Paskins, Sanders, Croft, & Hassell, 2017). They are therefore suitable for the exploration of the needs and characteristics of the EWD in real-life context. Videos also provide a space for natural interactions, authentic responses, and most importantly, embody expressions that are easily overlooked. It is indeed challenging to interpret some of their expressions, as syndromes and conditions associated with dementia are yet to be fully understood. But video recordings, on the other hand, make it possible for researchers to iteratively approach the context-specific meanings behind their expressions and generate practical knowledge responding to their needs.

In addition, videos create a reflexive learning environment for practitioners to review and develop their practices. Caregivers spend extensive time with the EWD, and their attitudes and responses construct the environment the EWD live in. Their knowledge of and experience with the EWD can greatly help in implementing need-based interventions (Kitwood, 1990). Unfortunately, the caregivers' practice wisdom is seldom documented and made visible in intervention

development. In addition, interventions developed outside the caregiving context are comparatively difficult to implement because they may inadequately accommodate the physical and psychological burden of institutional caregiving (McKenzie, Brown, Mak, & Chamberlain, 2016). Probably due to the low adaptability to specific contexts and ecology, interventions with high-internal validity are frequently proved unsustainable in real-life situations (W. L. Miller & Crabtree, 2005). W. L. Miller and Crabtree (2005, p. 341) described the reports of randomized clinical trials as "the cold sound of the intervention and faint echoes of the investigator's biases" and point out that they purposefully silence the "cacophonous music of patients, clinicians, corporate interests, habitats, community agencies, corporate staff and family turmoil."

In this study, two video-based methods, VEFI and PV, respectively, were applied in accordance with the principles of PAR. In this article, the added value, the operation procedure, and the ethical concerns of these methods are discussed.

Video Elicitation Interview

Video elicitation interview is a research method that utilizes video clips to prompt the participants to more extensively discuss certain issues. There is a long history of using video recordings to analyze professional interactions (Arborelius & Timpka, 1990; Asan & Montague, 2014; Henry, Forman, & Fetters, 2011). Originally, video elicitation interviews were used for training counselors to identify overlooked reactions of their clients during counseling sessions (Henry & Fetters, 2012). This interpretation process is usually guided by experts, and the video recordings are used as an objective reflection of reality. As a comparatively top-down approach to knowledge transference, this kind of research usually contains predetermined interpretative frameworks, which to some extent, restrict democratic production of knowledge.

Video elicitation interviews are also used to compare the participants' expressed values, emotions, and thinking with the interactions observed from the video recordings. This process potentially leads to a more comprehensive understanding of the participants' sensemaking mechanism. Videos are also particularly useful in the investigations of the sociocultural components embedded in interactions (Henry & Fetters, 2012). In addition, the research participants can review their own actions to enrich their sensemaking process and provide more informative accounts (Paskins et al., 2017). Videos are often recorded from a certain perspective, however, and may reflect certain values or biases (Mondada, 2006). The purposes behind videotaping may shape the reality the recordings capture. Both the video recording process and the sequential analyses are labor intensive, and most studies adopting this method only include very small samples. Therefore, it should be noted that it is inevitable for sampling to be biased in these studies.

In the current study, VEFI, namely focus group interviews (Rabiee, 2004), using video recordings of the intervention sessions as stimuli, were conducted among the practitioner-researchers. The researcher facilitated an interview after each intervention session, with a total of eight interviews conducted. Open dialogues were encouraged, and the focuses of the interviews varied, including collective reflections on the intervention sessions, sharing of experiences, identifying competent practices, and creating new ideas for the coming sessions. Critical reflexivity, creativity, and coping flexibility of the practitioners were fully encouraged during the interviews. It was found that in general, the practitioners have already developed their own skills and knowledge pool, and what hindered them in practice was not the lack of tool kits, but the lack of a metatheory that fully integrates their skills and knowledge in response to emergent needs of the clients (Sommerfeld, 2014). VEFI provide them with an interactive learning environment in which they can build their practice system and gain new knowledge from their own practice experience.

PV

PV refers to the collaborative filmmaking process within a certain group or community (Lunch & Lunch, 2006, p. 11). Instead of a single data collection method, the process itself is an intervention that raises awareness, empathy, and a sense of identity (Zoettl, 2013). The use of PV can result in more than community education: It has the potential to strengthen the sense of belonging within the community, too (Chiu, 2009). Video production further serves as a tool to bring indigenous and peripheral knowledge to the center (Knoblauch, Baer, Laurier, Petschke, & Schnettler, 2008) and encourages input from community dwellers with diverse backgrounds, contributing to the development of culturally competent health promoting programs (Chiu, 2009). In addition, it potentially empowers the marginalized groups by granting them an opportunity to make their voices heard (Zoettl, 2013) and provide them with a platform to demonstrate knowledge generated within the community (Tremblay & Jayme, 2015). In terms of social impact, PV efficiently document injustice embedded in the social phenomena and project voices and actions of justice. It is by nature committed to actions and changes and opens up new dialogues among concerned stakeholders (Cahill & Bradley, 2011). There are practical and ethical concerns regarding this method. Whose voice(s) does/do the end product represent? How to guarantee that the final video reflects justice and democracy within the community? Who will be the audience? How to disseminate the results and bring about social impact? How to protect the privacy of the participants in the long term? Multiple obstacles in emancipation and empowerment exist: The power structure within the community may dominate the research, the heterogeneity and even conflicts within the community may make it impossible to reach agreement regarding the research agenda, and the assumption that the target group needs to be seen and heard can also be problematic (Zoettl, 2013).

Epistemological Stance

Eventhough in certain circumstances scientific methods may not lead to the most relevant and worthy knowledge, the

monopoly of scientific truths has long been the focus in health research, rendering the context and alternative bodies of knowledge been constantly overlooked (de Sousa Santos, 2007). Whether studies should be conducted to answer the question of truth and falsehood depends on the intentions behind the production of knowledge: Is knowledge produced for social regulation or social emancipation (de Sousa Santos, 2007)? It is argued that the attempt to justify action research under positivistic ideology hinders its development, as action research is designed to supplement what positivistic research lacks (Kemmis & McTaggart, 2005). The dismantling of the myth of objectivity has long been in existence (Barbera, 2008), and multiple alternative epistemologies (Tsang, 2000) as well as inquiry paradigms (Israel, Schulz, Parker, & Becker, 1998) have been provided.

With the commitment to understanding complex issues in particular contexts and bringing about real changes, PAR needs to provide a space where different standpoints and perspectives interact, and therefore epistemological eclecticism and methodological pluralism are sometimes inevitable (Tsang, 2000). It has been argued that empirical data are mostly collected under the guidance of a certain theoretical framework, and thus to some extent, they are limited and regulated by presumptions (Køppe, 2012). Consequently, it is not uncommon that the social reality revealed in video-based methods differ from both positivism-driven approaches and social constructivism-based methods. What is needed is to bridge those two epistemological stances by creating a space that include both. To some extent, videos increase the level of objectivity; alternatively, they are still produced from a certain perspective and their interpretations vary. It is an integrative approach to social reality (Knoblauch et al., 2008).

In the past two decades, increasingly participatory media projects have taken place in different regions around the world aiming at revealing people's experience of certain social issues from their own perspectives (Luttrell & Chalfen, 2010). In this study, video elicitation interviews and PV are integrated under the participatory paradigm and are used as tools to transfer marginalized voices, lived experience, and practical wisdom into actions.

Method

Data were collected in a nursing home in Hong Kong. Data collection and analyses were guided by the principles of PAR, which mainly include three elements: collective knowledge production, reflexive cycle, and practical or social changes (Kemmis & McTaggart, 2005). VEFI were applied to achieve the first two goals, and PV were used to document the values and beliefs as well as further provoke changes. Adapted from the protocol proposed by Chávez et al. (2004), the current study included seven procedures: (1) recruiting the EWD that will experience the intervention, (2) recruiting stakeholders, (3) collecting informed consents, (4) forming working alliance among all practitioner-researchers, (5) starting a collaborative service development cycle based on VEFI, (6) generating

practical and theoretical knowledge collectively, and (7) using PV to produce short films for community education.

Eighteen EWD participated in this study as players in the play program. One service manager, eight frontline practitioners, eight community-dwelling volunteers, and one academic joined the study as practitioner-researchers to form a working alliance with the researcher. This study was approved by the Human Research Ethics Committee of the University of Hong Kong, and all participant researchers as well as family members of the EWD participants provided both written and oral consent. Developing a need-based play program for the EWD was a goal that every participant in the research agreed on. The study aimed to explore the lived experience of the EWD through collaborative, reflexive discussions, and develop a bottom-up play intervention that is sustainable within the institute. All participants and practitioner-researchers gave their consent to the video recording and the circulation of the video clips within the institution.

Data Collection

The reflective cycle that links experience and intelligent action is the scientific core of the PAR. In every PID session, the researcher organized a planning session in which the practitioners based on their own expertise and reflections from earlier weeks, collaboratively designed game plans. The practitioners then carried out the intervention, and practitioner-researchers took turns to videotape the intervention sessions. After the intervention, the researcher facilitated a VEFI in which everyone shared his or her experience of the intervention, reflected on his or her observations and insights, and generated new plans for the next session (Kemmis, McTaggart, & Nixon, 2013, p. 89). The cycle was repeated weekly for 8 weeks when the implementation of the interview ended.

Another major principle of action research is the goal to bring about change, since the change process is an important element (McVicar, Munn-Giddings, & Abu-Helil, 2012). In the context of the current study, PV was applied as a way to document knowledge and provoke changes at a larger scale. Short films made from the footage of the video recordings successfully demonstrated the heterogeneity of the EWD (Ludwin & Capstick, 2015), the complexity and opportunities in dementia care, and generated theoretical and practical insights. A critical and equal space was also created for this process (High, Singh, Petheram, & Nemes, 2012), and diverse voices of the practitioner-researchers were included in this project. Kemmis, McTaggart, and Nixon (2013, pp. 159–163) proposed the following ethical principles for PAR:

- The research should cause no harm to all participants involved and affected;
- The research should avoid injustice in the process;
- The research should be undertaken in the interests of the people involved;
- Informed consent and assent should be gained from every participant;

- Confidentiality and anonymity should be protected; and
- The research design should be sensitive to the underlying power dynamics in the social relationships among the participants.

These principles are also applicable in video-based methods. Due to the physical and mental vulnerability of the EWD, operation of these principles can be challenging (Dresser, 2000). Not only should the researchers minimize the harm to the EWD but also try to leave them with a sense of support and achievement (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). All games in this study were designed to accommodate the physical capacity of the EWD, supervised by dementia care professionals, and took place in a nursing home equipped with medical support. Although written consent was obtained from family members of the EWD participants, it is still important to respect the EWD's feedback and decisions during the study (Dewing, 2007; Hubbard, Downs, & Tester, 2003). To prevent confusion among the EWD, consent was sought throughout the study through verbal and nonverbal reactions to maintain a person-centered relationship between the EWD and the practitioners (Dewing, 2007). For example, when the EWD expressed discomfort or refusals during a game, the facilitator would actively rearrange the games according to their requests. If the discomfort continues, practitioners would assist the EWD to leave the table for a while until they decided to rejoin the group. These temporary withdrawals would later be discussed within the groups with a view to generate better ways to address the needs of the EWD in the play sessions.

Context for Data Collection

Contents of the videos reflect the perspectives and actions of the researchers because the angle from which a video was shot can be loaded with meaning. Hence, the videos should not merely be treated as a complete reflection of the one and only reality, instead, as a social practice guided by certain assumptions and orders. In-depth analyses of the videos yield insights into the cultural beliefs, sensemaking schemes, social norms, and dominant ideology in a social process (Mondada, 2006). It is conceded that the situation in which data are constructed is largely missing in conventional inquiries (Knoblauch et al., 2008); however, interactions are constantly constructed in specific contexts. Therefore, exploring what particular features influence and frame the current interactions leads to more comprehensive understanding of the process (Mondada, 2006). In addition, the details preserved by the videos enrich the description and reflection on the situations where actions emerge, foster insights not only on the individuals but also on the environment.

In this study, to maximize the capturing of authenticity and spontaneity of the EWD, the video recording took place in a nonintrusive way. Normally, research participants are aware of cameras and perform differently in video-based projects. In contrast, the EWD in this study constantly ignored the cameras and performed spontaneously in the play groups. Cameras were positioned at corners so as to minimize the influence. It appeared that the EWD in this context did not consider cameras an invasion of their privacy as the younger generations do. This may be partly due to the cameras being located everywhere in the institute, and the EWD have become used to them. Before viewing the video recordings, all practitioner participants were provided with an orientation on nonjudgmental interpretation of the video materials and confidentiality issues.

Analytical Approach

Data analyses in this study were collaborative, reflexive, and iterative. Consistent with the participatory paradigm (Banks et al., 2014; Chambers, 1994), democratized knowledge production and emancipatory practices were at the core of the analyses in this study. Democratization of research prioritized inclusion of the voice of all stakeholders at every level of the research, especially those of the marginalized group (Edwards & Brannelly, 2017). The meaning of this is 3-fold. First, it gives a voice to all stakeholders; second, it opens up a space where subjectivity and emotions are made accessible, potentially providing new perspectives and entry points for the current issues; third, it creates a learning space for all stakeholders to reexamine the contexts of their practices and gain new insights (Kemmis & McTaggart, 2005). To incorporate these principles into data analyses, a co-inquiry group (Banks et al., 2014) consisting of researchers, professional practitioners, and volunteers who participated in the play program collaboratively analyzed the video recordings within the VEFI. After each VEFI, there is a reflection session in which the co-inquiry group cooperatively transfers the analyses into intervention planning for the next week (Banks et al., 2014; Lorenz, 2010). The validity of data analyzes in this study was achieved through collective reflexivity and action implementation, instead of generalizability (Lykes, 2010).

Verbatim transcription of the video recordings was not available to the co-inquiry groups during the VEFI, but concurrent note-taking, reflective journaling, and reviewing important visual moments were utilized to enrich the reflection session (Halcomb & Davidson, 2006). To resist a single orientation in the analyses (Luttrell, 2010), the co-inquiry groups used different, yet proliferating analytical frameworks. Practitioner researchers adopted an analytical framework consisted of needs, characteristics, circumstances, and capacities (Tsang, 2013, p. 16) to present their understanding of each EWD and evaluate the practices during the interventions. This framework had been applied for 5 years within the nursing home, and the practitioners were familiar with it. The main objective was to identify the EWD's *needs*, and this is achieved through analyses of the EWD's *characteristics*, *circumstances*, and *capacities*. Characteristics include personalities, patterns of thinking and behaviors, and internalized culture; circumstances, in this context, refer to the available assistance to the EWD, and the relationships they live in; capacities are divided into physical, cognitive, and mental capacities. Volunteers from the community brought in immediate experience and feedback during the

reflection session, adding a new angle to the analyses. The researcher was trained in grounded theory methodology, and conducted preliminary thematic analyses of the VEFI, and negotiated the findings with other coresearchers to finalize the themes generated from each reflection session. Based on the results, the co-inquiry groups cooperatively discussed practice plans for the next session, extracted practice principles, and organized theoretical breakthroughs.

Although this approach may partly compromise the rigorousness of the analyses, and in certain situations, even intentionally detheorize and dephilosophize the process (Edwards & Brannelly, 2017), the collective analytical process did, however, lead to the discovery and reconstitution of the marginalizing beliefs, discourses, and practices within the institute, while challenging the stereotypical image of dementia at a community level.

After eight analytical sessions, a special reflective session was conducted focusing on video selection for the PV making. The footage was produced by the practitioners, volunteers, and researchers, reflecting diverse standpoints. The selected video footage was presented to the EWD and reorganized according to their opinions. Then, the final editing was conducted by an executive assistant within the institute.

Films created through the PV are usually circulated in public for educational and health promotion purposes. In this study, several family caregivers of the EWD participants expressed concern regarding disseminating the actual video recordings, considering the possible stigma of dementia within the society. After discussion, to keep the identities of the EWD confidential, the co-inquiry group in this study decided to hire volunteers that previously participated in this program to be actors and remake the film scenes. Although the actors stayed closely to the real-life situations and interactions, certain authenticity was still lost in the remade films. The decision was made to prioritize the privacy, safety, and best interests of the EWD participants. It should be appreciated that this dilemma between anonymization and giving a voice constantly exist in participatory visual research (Yang, 2015). To maintain the authenticity of the images and representation of their voices, the EWD were offered an opportunity to discuss and negotiate their self-representation during the video-making process (Yang, 2015).

Findings

Enriched and Equalized Learning Environment for the Practitioners

One obvious strength of the VEFI is the interactive learning environment they create. Video recordings provide rich data of the intervention process, unveiling many significant details that can deepen the practitioners' understanding of the EWD's needs. Close attention is paid to all details including attention, facial expressions, and micromovements of different body parts and speeches within the group. One personal careprovider stated:

Seldom do we have the opportunity to observe these EWD in such detail, let alone getting the meaning behind their behaviours and expressions. I learned a lot about how to effectively observe them and find out their needs . . . . I've never imagined that their anger and anxiety can be caused by insecurity until my colleague pointed out what happened when they tried to make them feel safe . . . they really became more peaceful and learned to let go . . . it's just so interesting to know about their deeper feelings.

In the process of collaborative interpretation, sometimes, the hierarchy among practitioner-researchers was dissolved, and an equal learning environment created. One social worker said:

There seems to be no distinction between leaders and subordinates in this program. Professionals can be wrong, especially when we are limited by previous experience with or bias towards the EWD. People of other backgrounds can provide new angles to look at the EWD. Everyone is equal when we tried together to understand the needs of the EWD. If not for the video-viewing, I wouldn't know of the mistakes that I might have made many times. It's important to admit that sometimes we really don't know why they're doing certain things or how to respond to them.

Diversified Interpretations of the Expressions of the EWD

Collaborative interpretation of the needs of the EWD often results in diversified explanations of a single act. Practitioner-researchers gradually found that whether a behavior is positive or negative is not as static as people normally imagine. In one reflexive session, there was a scene which caught everyone's attention when an angry old man suddenly calmed down as the practitioners started to push his wheelchair at high speed. One professional caregiver said:

I've been working with him for long and he's known for violent behaviours. He constantly shouted and even hit us. But today I suddenly think, maybe he's just super bored. Or maybe he's angry about being limited by the wheelchair. Knowing this, I'd feel better next time when I get hit by him (laugh)!

Counter-narratives of Dementia

In contrast to the commonly depressing image of dementia that has generated great anxiety and dread among caring professionals (McKenzie et al., 2016), during the VEFI, participant researchers in the current study have gradually constructed a different picture of dementia.

Many professional caregivers have overcome their fears toward the EWD and have changed their attitudes toward aging and deterioration in general. The language they used to describe the EWD and their own experiences of the play sessions have profoundly transformed as well. In one of the VEFI, the research participants were watching two older women passing a doll with gentle smiles, and one care worker said:

I was so amazed by them . . . . They've both lost their speech, and in daily caring work, we mostly hear them scream. But when they were passing the doll, it looked as if they were taking care of a baby together and sharing their experience. It's just so lovely!

At the last VEFI, when everyone was sharing their general experiences of PID, the same care worker said:

The most impressive moment would still be when Sandy passed the doll to Sarah. Their smiles, and the way they tried to talk . . . and they didn't speak the same language even before the disease impaired their speech. But they just connected! I'm new here and to be honest, I was quite afraid of them (the EWD) at the beginning, but now I find them cute. There's always a way to follow them. Their playfulness and happiness are beyond my imagination.

During play, the practitioners were also able to establish a relationship different from the one they have had with the EWD in their daily care work. Play was a realm where authentic empathy and emotions emerged. To a certain extent, reviewing these interactions in the group enabled the practitioners to transform their experience in the play groups into lived narratives and practice values, which sequentially become a new narrative of the EWD. Many scholars have advocated creating counter-narratives of aging and deterioration in the deficiency-focused discourses too (Conrad & Barker, 2010; Laceulle, 2017; Swinnen & de Medeiros, 2017), and the narratives constructed within this program, those that emphasize the playfulness, authenticity, and beauty of the EWD, are suitable alternatives.

Empowering Materials for Community Education

Being visible, or making oneself or somebody visible, is a form of symbolic power comparable to what Bourdieu called the "power of nomination" (Zoettl, 2013). The short films generated from this study demonstrate a counternarrative of dementia different from the normal imagination of this disease, which is bleak, hopeless, and depressing. During the play sessions, the EWD, on the contrary, frequently showed joy, creativity, care, and intelligence. A short film titled "Resuming hope" was made to display this unknown side of dementia. One senior service manager said:

In the past, I always felt bad for the EWD, thinking that they were so unlucky. Now after playing with them for so many times, I think dementia is no longer that scary. As long as they still have pleasure, social interactions and some freedom in their lives, life is not that hopeless . . . . As an ageing person myself, I find their performances encouraging and reassuring. And I believe these materials can really be useful in educating the mass public about dementia.

Discussion

VEFI as a Method to Bridge Research and Practice

VEFI can be an effective method to facilitate practitioners in building a more comprehensive understanding of the EWD through visualizing their practice experiences and creating a reflexive space. While working under the biomedical framework, practitioners tend to view the EWD through the healthy/morbid dichotomy (Foucault, 1973, p. 35) with an "anatomoclinical gaze" (Foucault, 1973, p. 126). Lived experience is organized by the "bipolarity of the normal and the pathological" (Foucault, 1973, p. 35), and the authentic experience of the disease may be silenced and ignored. Harris and Fiske (2011) consider the failure to recognize the internal life or mind of another is dehumanization, and this can often be the case in dementia care (Brannelly, 2011). During the 8-week VEFI, bodily expressions, emotional changes, and other embodied ways of being-in-the-world played an increasing important role in the practitioners' discussion. The VEFI helped the practitioners to go beyond the common health management scheme that promotes the healthy/morbid dichotomy and nurtured empathic appreciation as well as developed a holistic view toward the EWD they played with.

Exploration of the in-context sensemaking is another characteristic of the VEFI. Compared to standardized observations, the VEFI contain much more interpretation within the immediate contexts, relational, and personal. The behaviors and speech of the EWD are made sense of in specific situations and thus reflect personal significance. When evaluating the different capacities of the EWD, standardized measurements attach more significance to objectivity and decontextualized consistency, whereas the practitioners prioritize the interpersonal meaning of those particular capacities that carry personal significance for them. For example, in memory tests, the EWD are usually asked to remember things that do not carry relevant meanings to them, and often, they may not understand the meaning of doing these kinds of tests. In those circumstances, the EWD are forced to be assessed according to a set of externally imposed "normal standards" that make them susceptible to marginalization, or even objectification. In contrast, caregivers tend to evaluate the EWD's capacities in the immediate contexts, and it is usually the social or personal meaning of the demonstrated capacity that they appreciate. In this way, PV not only engaged the community but also amplified the voices and experiences once silenced and transformed them into new knowledge.

PV as a Method to Democratize Knowledge Production

PAR underlines a participatory paradigm in research and promotes a fundamental transformation of the nature of the research to create alternative perspectives and ways of understanding, to centralize research agendas around the problems concerned by the marginalized, and to achieve these agendas collaboratively (Edwards & Brannelly, 2017). Decisions in research are innately political (Bradbury & Reason, 2003), thus employing participatory visual methods such as PV can democratize the relationship between the researchers and the participants (Packard, 2008). Researchers, representatives from the community, as well as the EWD are all included in the video production to enable reconstituting the image of dementia from

diverse perspectives. This way, PV not only engage the community but also amplify the voices and experiences once silenced and transform them into new knowledge.

Limitations

There were a number of limitations present in this study. First, video-based methods are time consuming and resource demanding. Some participants were not familiar with media culture and visual technology, and the instructions on these topics potentially created an unequal power dynamic between the researchers and the participants (Packard, 2008). Second, due to the challenges the EWD encounter in giving informed consents, it is difficult to fully address the ethical issues. Research participants are more willing to be included in participatory media research when they understand the purpose and the dedicated audience of the study (Chalfen, Sherman, & Rich, 2010). However, it is very difficult for the EWD to maintain consistent understanding of and interest in the research objectives, resulting in the inevitable dominate position of the researchers and practitioners in some situations. Thirdly, collaborative data analyses, although enhancing democratic knowledge production and knowledge transference, may reduce theoretical rigor. The participatory visual methods are also represented at a midpoint instead of an end point (Luttrell & Chalfen, 2010). It should be acknowledged that extensive data have been generated in this study, and more in-depth analyses should be conducted in the future to enrich their theoretical implications. Fourthly, the preexistent assumption that the EWD are deprived and marginalized can be problematic because it may prevent researchers and practitioners from fully understanding the counter language, the resistance, and the agency of this group (hooks, 1990). Fifthly, this study only investigated a single context, risking the construction of a singular story of the EWD. Thus, more complicated and diverse visual narratives should also be produced to reflect the heterogeneity of this group.

Conclusion

In summary, this article demonstrates the strengths, limitations, and ethics of using VEFI and PV in PAR projects. Epistemologically, VEFI and PV validated alternative ways of knowing by generating meaningful, experiential knowledge (Denzin, 2017), and transferring it into actions (Banks et al., 2014). Integrating these two visual methods under the participatory paradigm is also an innovative methodological attempt to blur the "distinction between researchers, research informants and research users" and create collaborative impact among all parties (Banks, Herrington, & Carter, 2017). The impact of these methods is embedded in the changes of microprocesses within the practice context, the ways knowledge and power are negotiated, as well as the new images and narratives the EWD constructed.

In terms of practice improvement, VEFI is particularly effective in revealing the unseen details of the target population, stimulating constructive discussions, generating context-specific knowledge, and facilitating reflexive cycles. By comparison, PV provides space for the participants to demonstrate their voices, values, and experiences, which potentially lead to social changes in a larger scale. Researchers, nongovernmental organizations, and other institutes working with the marginalized groups can utilize these methods to enrich the practitioners' understanding of clients' lived experience, establish a democratic learning environment, and produce empowering materials for the vulnerable groups. The advantages of using video-based methods in PAR projects should be considered in conjunction with ethical issues, and the necessity and efficiency of the use of videos in PAR need to be evaluated based on the specific research questions and contexts.

References

Algar, K., Woods, R. T., & Windle, G. (2016). Measuring the quality of life and well-being of people with dementia: A review of observational measures. *Dementia*, 15, 832–857.

Arborelius, E., & Timpka, T. (1990). General practitioners' comments on video recorded consultations as an aid to understanding the doctor–patient relationship. *Family Practice*, 7, 84–90.

Asan, O., & Montague, E. (2014). Using video-based observation research methods in primary care health encounters to evaluate complex interactions. *Informatics in Primary Care*, 21, 161.

Banks, S., Armstrong, A., Booth, M., Brown, G., Carter, K., Clarkson, M., . . . Henfrey, T. (2014). Using co-inquiry to study co-inquiry: Community-university perspectives on research collaboration. *Journal of Community Engagement and Scholarship*, 7, 37–47.

Banks, S., Herrington, T., & Carter, K. (2017). Pathways to co-impact: Action research and community organising. *Educational Action Research*, 25, 541–559.

Barbera, R. (2008). Relationships and the research process: Participatory action research and social work. *Journal of Progressive Human Services*, 19, 140–159. doi:10.1080/10428230802475448

Benbow, S. M., & Reynolds, D. (2000). Challenging the stigma of Alzheimer's disease. *Hospital Medicine (London, England: 1998)*, *61*, 174.

Bond, J., & Corner, L. (2001). Researching dementia: Are there unique methodological challenges for health services research? *Ageing & Society*, *21*, 95–116.

Bradbury, H., & Reason, P. (2003). Action research: An opportunity for revitalizing research purpose and practices. *Qualitative Social Work*, *2*, 155–175.

Brannelly, T. (2011). Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics*, *18*, 662–671.

Cahill, C., & Bradley, M. (2011). *Documenting (in)justice: Community-based participatory research and video The Paradox of Urban Space* (pp. 223–239). Berlin, Germany: Springer.

Chalfen, R., Sherman, L., & Rich, M. (2010). VIA's visual voices: The awareness of a dedicated audience for voices in patient video narratives. *Visual Studies*, *25*, 201–209.

Chambers, R. (1994). *Paradigm shifts and the practice of participatory research and development*. East Sussex, UK: Institute of Development Studies.

Chávez, V., Israel, B., Allen III, A. J., DeCarlo, M. F., Lichtenstein, R., Schulz, A., . . . McGranaghan, R. (2004). A bridge between communities: Video-making using principles of community-based participatory research. *Health Promotion Practice*, *5*, 395–403.

Chiu, L. (2009). Culturally competent health promotion: The potential of participatory video for empowering migrant and minority ethnic communities. *International Journal of Migration, Health and Social Care*, *5*, 5–14.

Chui, C. H. K., Tang, J. Y. M., Kwan, C. M., Fung Chan, O., Tse, M., Chiu, R. L. H., . . . Lum, T. Y. S. (in press). Older adults' perceptions of age-friendliness in Hong Kong. *The Gerontologist*, *0*, 1–10.

Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior*, *51*, S67–S79.

de Sousa Santos, B. (2007). Beyond abyssal thinking: From global lines to ecologies of knowledges. *Review (Fernand Braudel Center)*, *30*, 45–89.

Denzin, N. K. (2017). Critical qualitative inquiry. *Qualitative Inquiry*, *23*, 8–16.

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, *6*, 11–25.

Downs, M. (2000). Dementia in a socio-cultural context: An idea whose time has come. *Ageing & Society*, *20*, 369–375.

Dresser, R. (2000). Dementia research: Ethics and policy for the twenty-first century. *Georgia Law Review*, *35*, 661.

Edwards, R., & Brannelly, T. (2017). *Approaches to democratising qualitative research methods*. London, England: Sage.

Foucault, M. (1973). *The birth of the clinic (AM Sheridan, Trans.)*. London, England: Tavistock.

Halcomb, E. J., & Davidson, P. M. (2006). Is verbatim transcription of interview data always necessary? *Applied Nursing Research*, *19*, 38–42.

Harris, L. T., & Fiske, S. T. (2011). Perceiving humanity or not: A social neuroscience approach to dehumanized perception. *Social Neuroscience: Toward understanding the underpinnings of the social mind* (pp. 123–134). Oxford Scholarship Online.

Henry, S. G., & Fetters, M. D. (2012). Video elicitation interviews: A qualitative research method for investigating physician-patient interactions. *The Annals of Family Medicine*, *10*, 118–125.

Henry, S. G., Forman, J. H., & Fetters, M. D. (2011). 'How do you know what Aunt Martha looks like?' A video elicitation study exploring tacit clues in doctor–patient interactions. *Journal of Evaluation in Clinical Practice*, *17*, 933–939.

High, C., Singh, N., Petheram, L., & Nemes, G. (2012). Defining participatory video from practice. In E.-J. Milne, C. Mitchell, & N. de Lange (Eds.), *Handbook of participatory video* (pp. 35–48). Lanham: AltaMira Press, US.

hooks, b. (1990). Marginality as a site of resistance. *Out There: Marginalization and Contemporary Cultures* (Vol. 4, pp. 341–343). Cambridge: MIT Press.

Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging & Mental Health*, *7*, 351–362.

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, *19*, 173–202.

Kemmis, S., & McTaggart, R. (2005). *Participatory action research: Communicative action and the public sphere*. Thousand Oaks, CA: Sage.

Kemmis, S., McTaggart, R., & Nixon, R. (2013). *The action research planner: Doing critical participatory action research*. Berlin, Germany: Springer Science & Business Media.

Kitwood, T. (1990). Psychotherapy, postmodernism, and morality. *Journal of Moral Education*, *19*, 3–13.

Knoblauch, H., Baer, A., Laurier, E., Petschke, S., & Schnettler, B. (2008). *Visual analysis. New developments in the interpretative analysis of video and photography*. Paper presented at the Forum Qualitative Sozialforschung/Forum: Qualitative Social Research.

Køppe, S. (2012). A moderate eclecticism: Ontological and epistemological issues. *Integrative Psychological and Behavioral Science*, *46*, 1–19.

Laceulle, H. (2017). Aging and the ethics of authenticity. *The Gerontologist*, *58*, 970–978.

Langa, K. M. (2015). Is the risk of Alzheimer's disease and dementia declining? *Alzheimer's Research & Therapy*, *7*, 34.

Liu, D., Hinton, L., Tran, C., Hinton, D., & Barker, J. C. (2008). Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross-Cultural Gerontology*, *23*, 283–299.

Liu, K. Y., Wong, B. H., Chu, M., & Leung, W. Y. (2018). *The continuum of care: A case study of a senior service centre for geriatric care in toronto, Canada sustainable health and long-term care solutions for an aging population* (pp. 71–90). Hershey, PA: IGI Global.

Lorenz, L. S. (2010). Visual metaphors of living with brain injury: Exploring and communicating lived experience with an invisible injury. *Visual Studies*, *25*, 210–223.

Ludwin, K., & Capstick, A. (2015). Using participatory video to understand diversity among people with dementia in long-term care. *Journal of Psychological Issues in Organizational Culture*, *5*, 30–38.

Lunch, N., & Lunch, C. (2006). *Insights into participatory video: A handbook for the field*. Oxford, UK: InsightShare.

Luttrell, W. (2010). 'A camera is a big responsibility': A lens for analysing children's visual voices. *Visual Studies*, 25, 224–237.

Luttrell, W., & Chalfen, R. (2010). Lifting up voices of participatory visual research. *Visual Studies*, 25, 197–200.

Lykes, M. B. (2010). Silence(ing), voice(s) and gross violations of human rights: Constituting and performing subjectivities through PhotoPAR. *Visual Studies*, 25, 238–254.

McCabe, M., You, E., & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. *The Gerontologist*, 56, e70–e88.

McKenzie, E. L., Brown, P. M., Mak, A. S., & Chamberlain, P. (2016). Nursing students' death anxiety associated with both age and illness of dementia patients. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 12, P976.

McVicar, A., Munn-Giddings, C., & Abu-Helil, C. (2012). Exploring the development of action research in nursing and social care in the UK: A Comparative bibliometric review of action research designs in social work (2000–2010). *Action Research*, 10, 79–101. doi:10.1177/1476750312439902

Miller, W. L., & Crabtree, B. F. (2005) Clinical research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research*. Thousand Oaks, CA: Sage.

Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia*, 15, 1141–1157.

Milne, A. (2010). *The 'D' word: Reflections on the relationship between stigma, discrimination and dementia*. Didcot, England: Taylor & Francis.

Mok, E., Lai, C. K., Wong, F. L., & Wan, P. (2007). Living with early-stage dementia: The perspective of older Chinese people. *Journal of Advanced Nursing*, 59, 591–600.

Mondada, L. (2006). Video recording as the reflexive preservation and configuration of phenomenal features for analysis. In Knoblauch, Soeffner, & Schnettler (Eds.), *Video Analysis*, 51–68. Bern, Switzerland: Peter Lang.

Murphy, K., Jordan, F., Hunter, A., Cooney, A., & Casey, D. (2015). Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia*, 14, 800–824.

Nygård, L. (2006). How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scandinavian Journal of Occupational Therapy*, 13, 101–112.

Packard, J. (2008). 'I'm gonna show you what it's really like out here': The power and limitation of participatory visual methods. *Visual Studies*, 23, 63–77.

Paskins, Z., Sanders, T., Croft, P. R., & Hassell, A. B. (2017). Exploring the added value of video-stimulated recall in researching the primary care doctor–patient consultation: A process evaluation. *International Journal of Qualitative Methods*, 16, 1609406917719623.

Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition Society*, 63, 655–660.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12, 240–249.

Seitz, D. P., Brisbin, S., Herrmann, N., Rapoport, M. J., Wilson, K., Gill, S. S., . . . Conn, D. (2012). Efficacy and feasibility of non-pharmacological interventions for neuropsychiatric symptoms of dementia in long term care: A systematic review. *Journal of the American Medical Directors Association*, 13, 503–506.

Sommerfeld, P. (2014). Social work as an action science. *Research on Social Work Practice*, 24, 586–600. doi:10.1177/1049731514538523

Swinnen, A., & de Medeiros, K. (2017). "Play" and people living with dementia: A humanities-based inquiry of TimeSlips and the Alzheimer's Poetry Project. *The Gerontologist*, 58.

Tremblay, C., & Jayme, B. D. O. (2015). Community knowledge co-creation through participatory video. *Action Research*, 13, 298–314.

Tsang, A. K. T. (2000). Bridging the gap between clinical practice and research: An integrated practice-oriented model. *Journal of Social Service Research*, 26, 69–90.

Tsang, A. K. T. (2013). *Learning to change lives: The strategies and skills learning and development system*. Toronto, Canada: University of Toronto Press.

Yang, K. H. (2015). Voice, authenticity and ethical challenges: The participatory dissemination of youth-generated visual data over social media. *Visual Studies*, 30, 309–318.

Zoettl, P. A. (2013). Images of culture: Participatory video, identity and empowerment. *International Journal of Cultural Studies*, 16, 209–224.