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Enhanced patient research participation: a Photovoice study in Blantyre Malawi

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ABSTRACT

Objectives Patient involvement in palliative care research is a desirable if challenging goal. Photovoice is an action research method in which affected communities gather photographs to document and discuss their communities' strengths and concerns. Engagement with policymakers is a separately stated goal. Photovoice is increasingly used in health-related research but has not been widely described in the palliative care literature. We report on experiences and lessons learnt using Photovoice in Blantyre, Malawi to encourage its wider use in research and practice.

Methods Thirteen co-researchers (six patients and seven household carers, mean age 47 years) receiving community-based palliative care, attended nine half-day group sessions over a 4-month period. Co-researchers produced, selected and analysed photographs. On completion of data collection, they conducted an advocacy event, including a photographic exhibition, to which media representatives and community leaders were invited.

Results Procedures to ensure safety of co-researchers and to obtain consent of individuals identified in the photographs were developed during the planning phase. Co-researchers engaged with the Photovoice process with enthusiasm, although frailty and physical disability (poor sight) limited participation for some older adults. Inclusion of palliative care staff within the research team helped to facilitate open dialogue and clinical review where appropriate.

Conclusions In this Photovoice study, patients and family members receiving palliative care engaged in an exploration of household well-being using photography, participatory analysis and an advocacy event. With appropriate planning, Photovoice can be adapted to a range of settings to enhance patient participation.

INTRODUCTION

Current evidence suggests that patients and families would appreciate greater

involvement in palliative care research.^{1–3} A patient-centred approach is at the heart of palliative care, and research methods should, where possible, reflect this, though concerns about patient vulnerability sometimes prohibit such involvement. Photovoice is a participatory action research method in which co-researchers combine photography with critical dialogue to record and reflect on their community's strengths and concerns (box 1). It was first described by Wang and Burris in 1997 who proposed its use among traditionally 'hard to reach' groups, encouraging a change in the traditional power dynamic of research, enabling the 'researched' to become the 'researcher'.⁴

A systematic review of Photovoice studies reported increasing use of the method in health research and included papers from African settings.⁵ In the palliative care literature, Horsfall and Noonan utilised Photovoice alongside other participatory methods to explore the impact of caring for dying patients on the wider community in Australia.⁶ Caregivers in New Zealand have also used Photovoice to explore their needs.⁷ Beyond the perspective of caregivers, Photovoice has been used by patients in a variety of challenging clinical settings: chronic pain,⁸ mental illness⁹ and cancer survivors,¹⁰ though it has not previously been described in the literature engaging patient participation in the setting of palliative care.

In this paper, we document our experiences and lessons learnt using Photovoice with patients and family caregivers affected by advanced cancer. This study was conducted at the community-based Tiyanjane Clinic in Blantyre, Malawi. Tiyanjane Clinic has provided adult palliative care services through government-linked hospital and community-based teams in



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Box 1 Goals of Photovoice methodology.

- ▶ To enable people to record and reflect their communities' strengths and concerns.
- ▶ To promote critical dialogue and knowledge about important issues through large and small group discussion of photographs.
- ▶ To reach policymakers.

Blantyre, Malawi (South Central Africa) since 2003. A stepwise overview of the process is recorded in order to encourage others to use Photovoice to facilitate patient participation in other settings of research and practice.

METHODS

In preparation for the study, two members of the research team attended a Photovoice workshop in London. This provided a practical and theoretical overview of Photovoice, as well as the opportunity to plan and develop our study design with support from the course facilitator and diverse range of participants.

Two weeks prior to recruitment, all households receiving community-based palliative care from Tiyanjane Clinic were approached by their palliative care community nurse with information about the study. Community-based volunteers already known to the households acted as fieldworkers, providing a point of contact in case of change in physical status, problems with cameras or any other queries. After obtaining their written consent for participation in the study, co-researchers (patients and main household carers) were provided with digital cameras and a basic introduction in their use.

Subsequently, the co-researcher group met twice a week over a period of 4 weeks. Between meetings, they took the cameras home to take photographs on the subject 'the story of my illness'. This broad subject area was chosen to make it as easy as possible to gather images, while ensuring that they had some relevance to an ongoing study exploring the well-being of households of patients with life-limiting illnesses. Hard copies of digital images were printed and sorted into categories as a group activity. Categories were discussed and named during a process of critical dialogue guided by an external facilitator trained in qualitative research. Towards the end of the meetings, co-researchers developed a programme of activities for an advocacy event which was held in a local community hall. Health and community leaders were invited to the event along with members of the media. In preparation for the advocacy event, co-researchers were invited to individually select photographs for which they wrote a short explanatory caption. These captioned images formed a photographic exhibition at the advocacy event. Secondary analysis of transcripts

from audio recordings of group discussions has been undertaken separately.

RESULTS

At the time of the study, 16 households under the community programme were approached, of which eight agreed to take part (comprising nine patients and eight carers). Engagement in research and use of cameras were new activities for all co-researchers in this study. Four older people (patients with brain, thyroid and oesophageal cancer and one carer) were excluded from the study as they were unable to use the cameras due to their illness (poor sight) or physical frailty. Long-term relationships between households and members of the community palliative care programme included in the research team helped to facilitate confidence and openness, though reflexivity was required to consider bias that this might introduce. Attendance at group sessions was good and co-researchers engaged enthusiastically during all Photovoice activities including the advocacy event (for which they all turned up early). Co-researchers were provided with transport money, a small amount of mobile phone airtime credit and lunch during the group meetings. One co-researcher (carer) missed some sessions due to the offer of paid work. Another one (patient) was admitted to hospital towards the end of the data collection period and later died. No cameras were damaged, lost or stolen during the research process, and the fieldworker volunteers were only contacted to request replacement batteries. Co-researchers did not report any problems as a result of having or using cameras in the community. A second process of consent for use of photographic images was included at the end of the data collection period. Separate consent was required for individuals not taking part in the study who could be identified in the images, some withheld their consent which led to the exclusion of these images. Twenty-seven captioned photographs were produced for display at the local advocacy event. These photographs have subsequently been displayed at local and international conferences and workshops.

DISCUSSION

Patient involvement in palliative care research is vital to enhance the patient-centred approach intrinsic to the WHO definition of palliative care. Fears of overburdening vulnerable patients have been expressed, though initiatives such as the Palliative and end of life care Priority Setting Partnership have begun to model the potential generated by such involvement.¹¹ Current evidence from high-resource settings suggests that patients and family members are keen to play a greater role in research.^{1-3 5}

Reviews of Photovoice research report its adaptability across a variety of cultural and contextual settings.^{12 13} Design of studies varies considerably in terms of setting, degree of participation, length, scope and number of co-researchers. The length of study

and frequency of meetings should be carefully planned with reference to degree of physical frailty and/or anticipated fluctuations in physical status of co-researchers. Studies like ours, taking place within the context of long-term services, could be improved by involvement of service users in the initial study design. Demands of the process (two meetings each week for 4 weeks plus an advocacy event) may have influenced those choosing not to participate in our study, though we did not illicit the reasons for non-participation. This would also introduce bias into the population, under-representing the views of those who are more seriously ill. In our study, four older people (average age 73, three patients and one carer) were unable to participate due to difficulties using the digital cameras. This problem should be less common in settings where co-researchers are already familiar with the use of cameras.

Although reimbursement for transport costs and mobile phone credit was included in our budget, some co-researchers missed sessions due to offers of temporary work. Compensation for lost working time may need to be considered if this study were to be repeated. Inclusion of palliative care nurses and community-based volunteers as part of the research team was designed to enhance safety of co-researchers throughout the process. Consideration of other practical issues—such as use of a community venue close to co-researchers' place of residence—also helped to minimise discomfort and/or drop out during the process. Hospital admission was required for one (patient) co-researcher who deteriorated during the study period. Review and transfer to hospital was overseen by the palliative care community nurse on the research team who also conducted the subsequent bereavement visit (accompanied by the community volunteers in accordance with local cultural practice).

Some of the other challenges of ensuring participation are tackled in a recent review of Photovoice research¹³ which also summarises ethical issues of importance when using participatory methods.

The final goal of Photovoice 'to reach policymakers' was of key interest to us when choosing this method. Access to palliative care and pain relief in low-income settings has been described as an 'abyss'¹⁴ and patient experiences are poorly understood.¹⁵ Statutory funding is typically prioritised to other areas of health. Co-researchers produced powerful visual representations of their daily household realities. These images have been displayed at a local advocacy event, at the medical school in Blantyre and at an international palliative care conference. Contacts made at the advocacy event led to an interview on a national television news programme where the lead researcher was invited to talk about palliative care.

Greater patient involvement in palliative care research should be encouraged. In our experience, with due consideration and careful planning,

Photovoice methodology can be used to yield rich and thought-provoking data for research and advocacy. Photovoice can be considered for adaptation and use in a variety of palliative care settings globally.

Contributors MJB compiled and drafted the original manuscript. JA, TM, SBS and LWN reviewed, contributed to and approved the final manuscript.

Competing interests None declared.

Patient consent None.

Ethics approval Ethical approval for the study was obtained from the College of Medicine Research Ethics committee (P07/16/1999) and the Research Ethics Committee of Liverpool School of Tropical Medicine (16-045).

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