

Use of Photo Methods in Research Studies with Cancer Survivors and Their Caregivers: A Scoping Review

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Abstract

Purpose: Photo methods such as photo-elicitation and photovoice have traditionally been implemented as knowledge-generation techniques; however, they have also been conceptualized as interventions. We performed a scoping review to document the use of photo methods in studies of cancer, to describe participant populations such as cancer survivors versus caregivers, types of cancers involved, and to identify opportunities for future directions.

Methods: An a priori search strategy was implemented across health-related databases with the following inclusion criteria: 1) study participants were diagnosed with cancer and/or were caregivers of those with cancer; 2) study participants were asked to take and/or respond to photographs as part of the study protocol; 3) articles were published in peer-reviewed journals; 4) articles were written in English.

Results: Eighty non-duplicative articles were identified; of these, 30 articles describing 24 individual studies were included for review. All but one (95.8%) of the studies utilized photovoice solely as a knowledge-generation technique without participant outcome measurement or analysis. Across all included studies, participants were largely women with breast cancer; other demographic and cancer-related variables (e.g., race, cancer stage) were not consistently reported. Caregivers were included in 37.5% of studies.

Conclusion: Photo methods are an effective method for eliciting rich qualitative data in cancer populations; however, there are missed opportunities in their lack of use for intervention and systemic change. In addition, inconsistent reporting of demographics and cancer characteristics limit our ability to synthesize these data across studies.

Background

The use of photographs in qualitative data collection is a powerful tool for eliciting rich narratives and generating knowledge about the experiences of a specific population. Several overlapping but distinct techniques exist for this purpose. Autophotography is a method rooted in anthropology that asks participants to take photographs of their environment, which are then used as data [1]. Photo-elicitation is the use of photographs—generated by participants or researchers—to guide participant interviews or focus groups [1, 2]. Photovoice is an engaging, collaborative method that specifically asks participants to take photographs reflective of their experience which are later used as prompts in interviews or group discussions [1–3]. As described by Wang and Burris, the three main goals of photovoice are to document strengths and challenges of individuals and/or communities; to use photographs to generate dialogue about important issues; to affect policy [3]. For the purposes of this review, all of these techniques will be encompassed by the umbrella term “photo methods.”

Historically, such photo methods have been used in qualitative research. More recently, photo methods have been explored and evaluated as a mode of intervention. Sitvast and Abma proposed that photo methods can be implemented to produce two broad outcomes: empowerment and meaning [4]. Both of these have the potential to be powerful strengths in the context of a chronic illness, particularly cancer. Empowerment and meaning-making represent critical precursors to constructs and processes such as self-efficacy, effective physician-patient communication, treatment decision-making, and post-traumatic growth [5–7]. Further, the social component of engaging in dialogue with others viewed as peers may contribute to enhanced perceptions of social support. In addition, the act of taking photographs can serve as a form of behavioral activation, resulting in decreased symptoms of depression [8].

The aim of this scoping review is to explore the literature regarding the use of photo methods in cancer populations (patients and caregivers) in service of answering the following questions: 1) What are the aims of studies that use photo methods in cancer populations?; 2) What types of cancers are represented in studies using photo methods?; 3) Which (if any) of the three goals proposed by Wang and Burris do these studies address?; 4) What gaps exist in the literature with respect to photo methods as knowledge generation and/or intervention for cancer patients and their caregivers?

Methods

The search strategy outlined in Table 1 was performed across the following health-related databases: MEDLINE (through Ovid), PsycINFO, EMBASE, and CINAHL. To ensure literature saturation, reference lists of included articles were evaluated for additional

relevant articles. Article information (title, authors, year, journal, abstract) was exported into a spreadsheet for eligibility assessment; duplicate entries were removed. Two independent reviewers (authors AL and LC) evaluated all results according to the following inclusion criteria: 1) Study participants had been diagnosed with any type of cancer or were caregivers of individuals diagnosed with any type of cancer; 2) Cancer patients/survivors and/or their caregivers participated in a study in which they were asked to take photographs; 3) Articles were written in English; 4) Articles were published in peer-reviewed journals. There was no restriction with respect to publication year. Discrepancies in initial eligibility coding were resolved via discussion and consensus between the two reviewers. Reasons for article exclusion were recorded.

Table 1
Search Strategy

Concept	Search Terms*
Photography	photojournalism OR photonarrative OR photo elicitation OR photo-elicitation OR photovoice OR photo-instrument OR photostory OR photostories
Cancer	cancer OR oncology OR malignancy OR neoplasm
Study participants	patient OR survivor OR caregiver
*Search terms between concepts were combined with "AND"	

Data Extraction

Data aligning with the aims of the scoping review were extracted for all included studies by two independent reviewers (authors AL and LC). Data were compared between reviewers and discrepancies were resolved via discussion and consensus between the two reviewers. Additional information related to participant demographics (e.g., age, sex, race) and cancer characteristics (e.g., treatment history, time since diagnosis, cancer stage) was also extracted.

Review Aim 1: Study Goals and Aims. A study was considered to be an intervention if it met the following criteria: 1) constructs of interest were assessed quantitatively before and after the implementation of photo methods; 2) the explicit intent of photo method utilization was to produce change in the constructs measured. The aim of a study was considered to be qualitative if its primary intent was to generate and summarize information using qualitative analytic methods. A study was considered to be mixed-methods if it met criteria for both intervention and qualitative study types.

Review Aim 2: Study Populations. Cancer diagnosis of study participants was abstracted from demographics tables when available; otherwise, the full text was reviewed in order to determine whether this information was reported for the sample.

Review Aim 3: Wang and Burris Criteria. With respect to determining whether studies addressed the photovoice goals described by Wang and Burris, the following criteria were employed: a study was considered to document the strengths and challenges of individuals/communities if these topics were either generated by participants or pre-determined by researchers. A study was considered to generate dialogue if participants discussed their photographs with one another; if participants discussed their photographs with only the researchers (i.e., via individual interview), this was not considered to generate dialogue. Lastly, a study was considered to affect policy if the article included an explicit description of how the photographs and/or discussions thereof were used to engage policymakers and/or community stakeholders. Since we focused on a medical population, we also assessed whether a study intended to use photo methods to affect healthcare practices. A study was considered to affect healthcare practices if the article included an explicit description of how the photographs and/or discussions thereof were presented to healthcare providers and/or administrators.

Results

The search strategy returned 80 non-duplicative results; of these, 30 articles were determined to meet all inclusion criteria. Articles describing the same study population and/or inquiry were collapsed and results are reported across articles. In total, the 30 articles described 24 individual studies.

Table 2
Study Characteristics

First Author, Year	N (Survivors)	N (Caregivers)	Aim	Cancer type(s)	Document strengths / challenges?	Generate dialogue?	Affect policy?	Affect healthcare practices?
Che, 2021 [9]	14	0	Qualitative	Breast	Yes	No	No	No
Capewell, 2020 [10]	20	0	Qualitative	Breast	Yes	Yes	No	No
Lopez, 2005 [11]	11	0	Qualitative	Mixed	Yes	No	No	No
Park, 2020 [12]	9	0	Qualitative	Breast	Yes	Yes	No	No
Pailler, 2020 [13] Beaupin, 2019 [14]	30	0	Intervention	Mixed	Yes	Yes	No	No
DeGuzman, 2019 [15]	7	0	Qualitative	Mixed	Yes	No	No	No
Pini, 2019 [16] Pini, 2019 [17]	12	0	Qualitative	Mixed	Yes	No	No	No
Pritlove, 2019 [18]	12	0	Qualitative	Mixed	Yes	No	No	No
Bates, 2018 [19]	6	7	Qualitative	Not Reported	Yes	Yes	Yes	Yes
Wong, 2019 [20]	13	7	Qualitative	Pancreatic	Yes	Yes	No	No
Edwards, 2017 [21] Edwards, 2018 [22]	286	30	Qualitative	Mixed	Yes	No	Yes	No
Hammond, 2017 [23]	24	19	Qualitative	Mixed	Yes	Yes	No	No
Kim, 2017 [24]	0	5	Qualitative	Hematological	Yes	Yes	No	No
Morrison, 2015 [25] Morrison, 2015 [26] Morrison, 2014 [27]	20	0	Qualitative	Mixed	Yes	No	Yes	Yes
Yi, 2016 [28]	7	0	Qualitative	Mixed	Yes	No	No	No
Moore, 2013 [29]	11	0	Qualitative	Not Reported	Yes	No	No	No
Mosavel, 2010 [30]	7	13	Qualitative	Not Reported	Yes	Yes	Yes	Yes

First Author, Year	N (Survivors)	N (Caregivers)	Aim	Cancer type(s)	Document strengths / challenges?	Generate dialogue?	Affect policy?	Affect healthcare practices?
Yi, 2010 [31]	6	6	Qualitative	Mixed	Yes	Yes	No	No
Frith, 2007 [32]	19	0	Qualitative	Breast	Yes	No	No	No
Oliffe, 2007 [33]	19	0	Qualitative	Prostate	Yes	No	No	No
López, 2005 [34]	12	1	Qualitative	Breast	Yes	Yes	Yes	No
Polo, 2021 [35]	13	0	Qualitative	Mixed	Yes	Yes	No	No
Kim, 2021 [36]	0	5	Qualitative	Mixed	Yes	Yes	No	No
Poudrier, 2009 [37]	12	0	Qualitative	Breast	Yes	Yes	Yes	No
Brook, 2008 [38]								

Assessment of Included Studies' Goals and Aims

Only one study used photo methods for the purposes of intervention. The sole intervention was the Photographs of Meaning Program for Adolescent and Young Adult (POM-AYA) cancer survivors [13, 14]. POM-AYA is a 10-week intervention delivered via a study-specific social media platform. Weekly intervention topics, adapted from Meaning-Centered Psychotherapy, were distributed to participants who were then asked to upload at least 2 pictures reflecting that topic. Participants were also asked to describe each photograph and its connection to the weekly theme using audio or text narration. As with other social media platforms, participants could view, "like," and comment on others' photographs, providing opportunities for social interaction and expansion upon themes. In an assessment of feasibility and preliminary efficacy, 30 participants were enrolled in POM-AYA; however, 15 demonstrated minimal engagement in the intervention [13]. Of the 15 participants who completed the full 10-week intervention, reported program satisfaction was extremely high. Measures of depression, quality of life, and spiritual well-being were completed at baseline, immediately post-intervention, and 2 months post-intervention. Post-intervention improvements were seen with respect to depression and quality of life, and these effects were maintained at the 2-month post-intervention follow-up; however, there was no change in spiritual well-being.

The subject of qualitative inquiries varied, with the majority of studies focusing either on a particular population/community (i.e., Malay women with breast cancer [9]; people with advanced cancer in Blantyre, Malawi [19]; South African cancer survivors [21, 22]; First Nations women seeking cancer care [23]; Aboriginal Canadian survivors [29, 30]) or a specific cancer-related issue (i.e., cancer-related sexual dysfunction [9]; return to work/school [16–18, 25–27]; engagement in health behaviors after cancer [11, 12, 15]).

Study Populations

With respect to studies involving a specific cancer type, breast cancer was the most common ($k = 6$), with other cancer populations including hematological ($k = 1$), pancreatic ($k = 1$), and prostate ($k = 1$). The majority of studies included more than one cancer type ($k = 12$); however, for reports in which a diagnostic breakdown was presented, breast cancer survivors comprised the majority of these samples. Very few studies reported cancer stage, cancer treatment history, or time since diagnosis for participants. A similar pattern emerged with respect to reporting of participant demographics such as age and race, though the majority of studies did report participant sex. Only one study assessed an entirely male sample due to its focus on prostate cancer.³³ Nine studies recruited entirely female samples, and the composition of the remaining mixed-sex samples was largely female. Caregivers represented

16.3% of all participants and were included in 9 of the 24 studies. Only 2 studies focused solely on caregivers, both of which explored the experiences of Korean mothers whose children had cancer [24, 36].

Wang and Burris Criteria

Documenting Strengths and Challenges. All included studies fulfilled criteria for documenting the strengths and challenges of the larger population or community represented by study participants. This was accomplished by asking participants to photograph and/or reflect on both sides of the issue at hand—for example, barriers and facilitators to accessing care; psychological distress and coping strategies; negative and positive cancer treatment experiences; limitations and advantages of family caregiving.

Generating Dialogue. Just over half (54.2%) of included studies provided an opportunity to generate dialogue among participants. This was typically achieved by holding one or more in-person small group sessions where participants were asked to bring their photographs, present them to the group, and engage in facilitated discussions based on emergent themes. The articles that did not generate dialogue among participants typically consisted of one-on-one interview(s) with research staff. While this represents a type of dialogue, it is qualitatively different than one wherein participants can share their experiences with one another and generate feelings of camaraderie, relatedness, and support from others with similar backgrounds.

Affecting Policy and/or Healthcare Practice. Six studies included a specific effort to engage community stakeholders and policymakers in discussions regarding study findings; of these, 3 studies also engaged healthcare administrators and/or providers (Table 3). Though these studies aligned with Wang and Burris’ criterion of affecting policy, none described a specific policy or healthcare practice change achieved as a result of study. However, it is possible that such outcomes may be forthcoming in a future paper.

Table 3
Descriptions of Community and Healthcare Advocacy

First Author, Year	Description
Bates, 2018 ¹⁹	Advocacy event featuring 27 curated photovoice images in order to report findings to local health and community leaders and media
Edwards, 2018 ²²	Photographs have been used in a variety of settings including public exhibitions, policy advocacy, information brochures, and a cancer advocacy toolkit
Morrison, 2014 ²⁷	Photographs alongside survivors’ descriptive narratives presented to physicians and industry stakeholders in order to enhance support for return-to-work
Mosavel, 2010 ³⁰	Public photo exhibit of selected images used in the photovoice project; event attended by health providers, community stakeholders, cancer survivors, and caregivers
López, 2005 ³⁴	Forum event led by its participants in which they presented their photographs and formed community taskforces in order to address the issues identified during the study
Poudrier, 2009 ³⁷	Participants in the study have developed relationships with community advocates and held several information dissemination initiatives

Discussion

Although only one of the studies aimed to build an intervention based on photo methods, many other studies reported anecdotal participant benefit. These benefits included processing their experience with cancer [10], feeling empowered and supported [22, 31], improvements in psychosocial stressors [28], and facilitation of discussions of topics that participants otherwise would have thought to be inappropriate to discuss with others [34]. However, since these outcomes were not quantitatively assessed, the extent to which photo methods serve as an intervention in a cancer population remains unknown. Indeed, a review of photovoice use in public health concluded that extant literature in this space does not typically provide information regarding outcome evaluations [39]. The only quantitatively-assessed outcomes of studies included in this review were depression, quality of life, and spiritual

growth [13], but these reports from additional studies reflect other potential outcomes of interest including social support, self-efficacy, and post-traumatic growth.

In accordance with the principles of a scoping literature review and in order to understand more about what a photo methods-based intervention for cancer survivors could resemble and achieve, we looked to literature in other populations with physical and/or mental illness. Identified studies fall under one of two categories: photo methods alone [40–42] or photo methods as part of a multi-component intervention [43, 44]. Lennon-Dearing and Hirschi developed a 7-week photovoice intervention for women with HIV to document their lives with the express purpose of providing community education [40]. Thus, photovoice was leveraged as an intervention for improving self-efficacy and empowerment by linking it with a broader community education event. Pre-post analyses demonstrated statistically significant improvement in coping self-efficacy. In a randomized pilot study by Werremeyer and colleagues, college students living with a mental illness were randomized to a photovoice group intervention or standard group counseling [41]. Those randomized to photovoice demonstrated a greater reduction in anxiety symptoms over the 8-week program compared to those in the group counseling condition. Wharton and colleagues designed a community education program in which family caregivers of individuals with Alzheimer's Disease attended four sessions led by a professional photographer. Before taking photos for a gallery display [42]. Participants were instructed in principles of photography and photojournalism (Session 1), and then spent the following three sessions viewing and discussing one another's photographs documenting the caregiver experience. Pre-post intervention results reflected a significant increase in caregiver burden and a reduction in depressive symptoms which did not reach the level of statistical significance, but did reflect clinical significance.

Two studies investigated the use of photovoice in the context of a multi-component intervention for individuals with diabetes [43, 44]. Leung and colleagues used photovoice over the course of a 6-week intervention consisting of group meetings, taking and discussing photographs, goal-setting, and developing action plans to promote increased physical activity as a management strategy to improve diabetes and hypertension [43]. Baig and colleagues integrated photovoice with an educational intervention and group discussion to encourage problem-solving skills, social support, and health behavior change [44]. Both studies conducted qualitative analyses of the themes present in photos taken by participants and also measured outcomes of interest. Both interventions produced positive effects on targeted outcomes including number of steps taken (via accelerometry) [43], lower body strength and limb flexibility (via fitness testing) [43], confidence in diabetes self-management [44], and social support [44]. While Leung and colleagues did not report data related to intervention adherence or satisfaction, Baig and colleagues found that 75% of participants attended at least one session and 52% took photos; in addition, 82% reported that they enjoyed discussing photos with other group members. However, because the control groups in these two studies were waitlist control [43] and enhanced treatment as usual [44], respectively, the extent to which photo methods uniquely contributed to improved outcomes in these multi-component interventions remains unknown.

All of the studies implementing photo methods as an intervention tool in the context of chronic physical or mental illness—including the one focused on cancer survivors [13, 14]—involved group discussion. Benefits of this include fostering relatedness and providing peer social support; however, reliance on facilitated group discussion also may pose potential barriers such as schedule conflicts and transportation difficulties. An alternative approach could be to formulate an individual-level photo method intervention such as integrating photo methods with expressive writing to create a self-directed intervention. Expressive writing interventions have been found to be effective in general populations [45]; however, in cancer populations, documented effects are small or null [46, 47]. Supplementing expressive writing exercises with accompanying photographs could bolster the effects on well-being among cancer survivors and reduce obstacles to attending in-person photo method group sessions. At the same time, expressive writing places a greater demand on individual literacy, whereas photographs eliminate the reliance on reading and writing abilities. Thus, future studies could investigate which methods or combination of methods work best for specific groups.

Study Limitations

Results of this review must be contextualized within its limitations. First, the decision to omit non-peer-reviewed sources may have resulted in the skew toward qualitative photo method studies in a cancer population—especially if other interventions had null findings. However, the authors decided a priori that published abstracts were not thorough enough to address the aims of this review. Further, at the time of writing, there were no current or planned studies registered in ClinicalTrials.gov that involved photo methods in cancer. Second, the authors were limited by language constraints and reviewed only studies published in English. Given

that many of the included studies took place in countries whose primary language is not English, it is possible that studies written in other languages that otherwise met eligibility criteria were not included in this analysis.

Clinical Implications

Despite focusing on a medical population, only three studies described an explicit effort to share findings with healthcare administrators and/or providers. None of these studies described what, if any, changes were made in a healthcare setting in response to photo-based investigations. Thus, there is significant opportunity for future studies to develop and evaluate initiatives in the healthcare setting based on themes that emerge from the use of photo methods. Based on the results of this review, photo methods appear to be a powerful approach to generating dialogue and understanding others' lived experiences—particularly with respect to topics that individuals are otherwise inclined to keep to themselves [33,34]. Oncology providers may find it helpful to ask their patients to share photos from their daily lives that represent their questions, concerns, and hopes for living with cancer, which may serve to improve communication between patient, caregiver, and provider [48]. A brief discussion of photographs during appointments may raise issues outside of providers' awareness such as psychological concerns, family dynamics, or treatment side effects which can then be addressed directly or through referral. At the same time, providers should be aware of the time and resources required to engage in photo methods and evaluate whether patients and/or caregivers have the actual equipment, time, and energy to take and reflect upon photos in order for the intervention to be successful, and that recording their experiences actually has weight (e.g., emotional catharsis from documenting experiences; contributing to an outreach event; lobbying for better policy).

Conclusions

Photo methods are an effective method for eliciting rich qualitative data in cancer populations; however, there are missed opportunities in their lack of use for intervention and systemic change. In addition, very few articles reported specific demographic and cancer-related characteristics of their sample. While this information may seem to be extraneous in the context of a single, focused qualitative investigation, its absence limits our ability to synthesize knowledge across studies in the future. For example, as additional photo method studies explore return-to-work after cancer, it would be helpful to know whether there are important differences between samples such as socio-economic status, race, and/or length of time since diagnosis that might influence the generalizability of findings across studies. Similarly, engagement in health behaviors after cancer—particularly physical activity—may be influenced by the type of treatment received. The majority of participants across studies were breast cancer survivors, which highlights opportunities for the use of photo methods in other cancer populations. For example, in their investigation of pancreatic cancer through the use of photo methods [20], authors found unique themes surrounding prognosis and stigma given the lack of screening and treatment options for this cancer. In addition, individuals with primary brain tumor have a particularly unique cancer experience given that, more than other cancer groups, experience greater direct and treatment-related effects on cognition, mood, and personality [49]; however, their experiences have not been explored via photo methods to date. Many opportunities for future research exist with respect to examining photo method interventions in the clinical healthcare setting.

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Figures

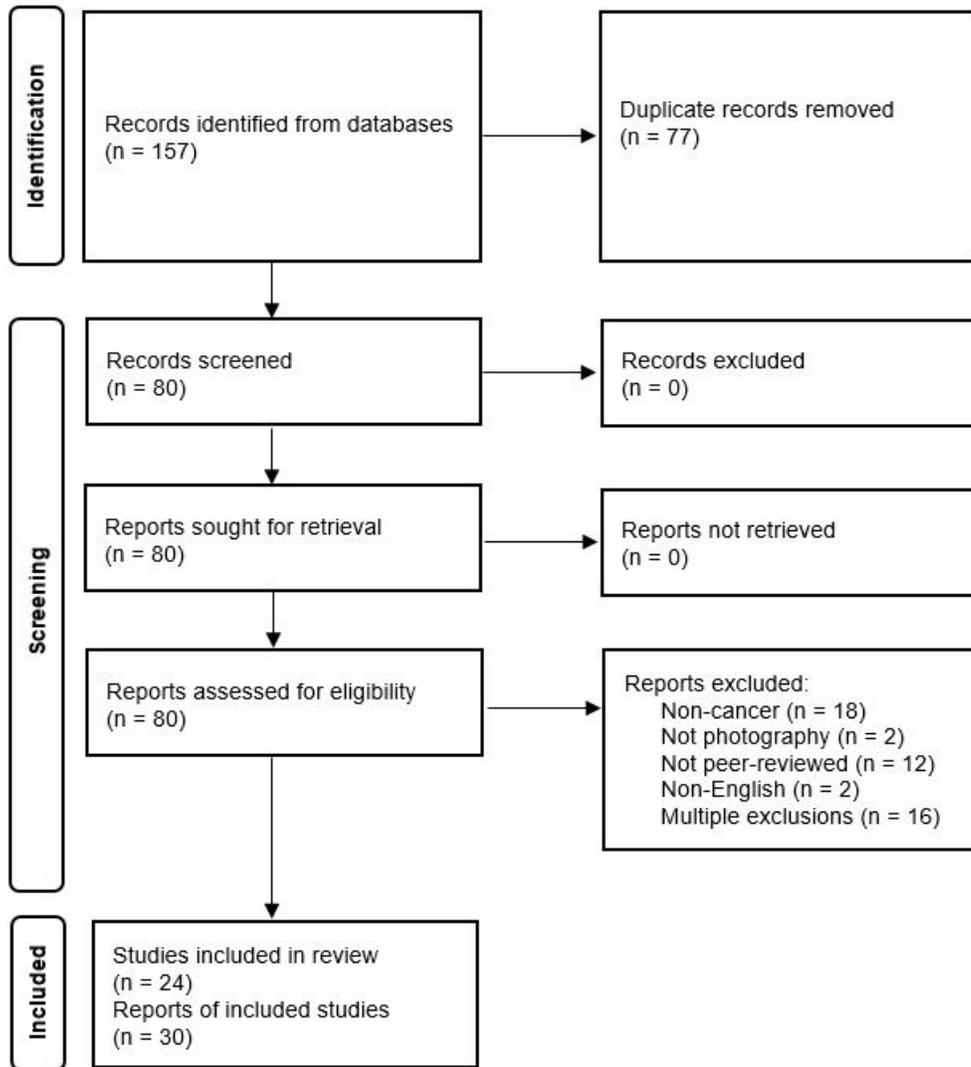


Figure 1

PRISMA Diagram