

Visual Storytelling: A Beneficial But Challenging Method for Health Research With Young People

Qualitative Health Research
20(12) 1677–1688
© The Author(s) 2010
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1049732310377455
http://qhr.sagepub.com


Sarah E. Drew,¹ Rony E. Duncan,² and Susan M. Sawyer³

Abstract

Visual storytelling is a new research approach drawing on established methods of photovoice and photo elicitation. It appears well suited to research with young people. We explored the feasibility of this approach, reflecting on benefits and challenges encountered while using it during a study of chronic disease self-management in adolescents. During in-depth interviews, 68 participants were questioned about the value of visual storytelling. Thematic analysis was applied. Visual storytelling was valued for (a) being a draw card during recruitment and increasing positive feelings about the research; (b) being fun; (c) promoting self-understanding; and (d) promoting expression, communication, and focus during interviews. Deciding what to photograph was difficult. More time and effort was required by researchers than for a standard qualitative interview study. The technique facilitated rich interviews, drawing into focus details of young peoples' lives that otherwise might not have been discussed.

Keywords

adolescents / youth; children, illness and disease; illness and disease, chronic; photography / photovoice; research design; stories / storytelling; visual methods

Undertaking research with young people can be challenging, especially when investigating sensitive topics such as sexual behavior, substance use, violence, and adherence to medical treatments. The last 10 to 15 years have seen a shift in research with young people, from the use of proxy reports from parents, teachers, and physicians to asking young people more directly about their behaviors and perspectives (Santelli et al., 2003). Procedures for this are relatively straightforward in quantitative research; for example, surveys are now designed for completion by young people. However, procedures are less straightforward for qualitative research with young people.

Qualitative approaches are valuable in researching the lived experiences of young people. Scholars of the sociology of childhood and youth studies have played an important role in emphasizing the importance of young peoples' competence as social actors, and the need to be sensitive to the way relationships between adults and young people are influenced by differential power resources (Matthews, 2007; White & Wyn, 2004). In response, the social sciences have shifted to focus more on children and youth as actors in their own right, playing a significant role in both shaping and being shaped by the social world (Cosaro, 2005; Matthews; Mayall, 2002; Tisdall, Davis, & Gallagher, 2009). Consistent with these youth-centered approaches is that qualitative researchers seek detailed information from

young people themselves rather than seeking information about young people (Matthews; Punch, 2002).

The fact that children and young people can be perceived as competent social actors does not necessarily mean that research should be conducted with them in the same way as it would be with adults (Baker & Weller, 2003). Shifting from a "top-down" approach to data collection can require innovation in research methods, as many established methods such as one-on-one interviews are heavily adult centered (Baker & Weller; Dresnick, 2006; Mauthner, 1997; Pole, Mizen, & Bolton, 1999). Researchers have been encouraged to carefully tailor qualitative research methods to more adequately explore young people's experiences (Matthews, 2007).

There remain, however, a number of challenges for such research. First is the challenge to make research interesting and appealing so as to foster young people's engagement within the research process, and promote

¹The University of Melbourne, Parkville, Victoria, Australia

²Murdoch Children's Research Institute, Parkville, Victoria, Australia

³The Royal Children's Hospital, Parkville, Victoria, Australia

Corresponding Author:

Sarah E. Drew, Centre for Adolescent Health, Royal Children's Hospital, 2 Gatehouse St., Parkville 3052 VIC, Australia
Email: drewse@unimelb.edu.au

young people's participation. The second challenge is to employ strategies that help to subvert traditional adult-child hierarchies, that foster communication and facilitate the sharing of opinions, perceptions, and information that might not otherwise be easy to share. Such strategies are important in promoting a comfortable research context in which young people are more likely to provide candid responses, and to feel that what they say will be valued. Third, in-depth methods must remain flexible to suit a range of development-related capacities for personal reflection and articulation of complex thoughts. This is particularly the case when study samples span a broad age group. For example, between the ages of 10 and 18 years (as in our study), young people are still developing the skills and capacities to readily consider and articulate complex understandings. This is influenced both by their degree of life experience and their maturing cognitive development. Qualitative research designs involving children and young people must take account of such considerations and employ strategies that help promote reflection and communication about issues that might otherwise be difficult to conceptualize and express.

In this article we outline the feasibility and utility of visual storytelling as a method of youth-centered data collection in a qualitative study of self-management in young people with chronic disease. Visual research has a long and diverse history, ranging from cultural studies and anthropology to marketing. Our focus here relates specifically to the use of participant-generated visual methodologies in the context of health research with young people. Visual storytelling draws on principles from the established methodologies of photovoice and photo elicitation. It also shares some aspects of the video intervention assessment (VIA) approach in terms of the focus on young people, chronic illness, and illness management, but the specifics of the video approach are quite different from our photographic approach (Patashnick & Rich, 2005). Both photovoice and photo elicitation have been used separately with young people (Bolton, Pole, & Mizen, 2001; Clark, 1999; Clark-Ibanez, 2007; Liebenberg, 2009; Moss, 1999; Rasmussen, 2004; Samuels, 2007; Streng et al., 2004; Walker, Schratz, & Egg, 2008), but not in combination. For example, Haines, Poland, and Johnson (2009) used both in-depth interview and photovoice approaches, but the interviews were completed prior to the photographic exercise and discussion of the images took place within a more conventional photovoice group discussion.

Photovoice was originally developed as a group-based participatory health promotion strategy (Wang, Yi, Tao, & Carovano, 1998). Its original conceptualization saw participants come together on the basis of a common interest or personal characteristic to take part in a group

photographic project. It is based on a community-development philosophy with emphasis on consciousness raising, empowerment, and promoting understanding of community issues. Participants are encouraged to focus on issues of greatest significance to them, and to photograph the "realities" of their everyday encounters and experiences. Once images have been created, the group comes together again to discuss the photographs and develop titles or descriptions of selected images. This is usually done with the goal of developing an exhibition for policy makers, health care providers, and other influential advocates. Within this methodology, images are seen as a powerful medium for communicating issues and promoting change (Carlson, Engebretson, & Chamberlain, 2006; Streng et al., 2004; Wang, Cash, & Powers, 2000); the emphasis is generally more on the images themselves (accompanied by a title) as research data, rather than on considering in depth what participants might say about the images. Rather than a group project, we were interested in exploring in-depth experiences separately with adolescents because we felt this would be more likely to result in candid discussion of sensitive topics. Thus, we adapted the original photovoice model for our visual storytelling approach, in which we replaced group discussions of images with individual in-depth interviews.

Because we wanted to keep the photographs integral to the in-depth interviews, we also drew on the principles of photo elicitation as an approach to in-depth interviewing (Clark-Ibanez, 2007; Collier, 1967; Fleury, Keller, & Perez, 2009; Harper, 2002; Oliffe & Bottorff, 2007; Packard, 2008; Punch, 2002; Radley & Taylor, 2003; Rasmussen, 2004; Samuels, 2007; Stuckey & Tisdell, 2010; Wang et al., 2000). This approach to interviews can involve researcher-generated or participant-generated photographs. Photographs are introduced to the research interview based on "assumptions about the role and utility of photographs in promoting reflections that words alone cannot" (Clark-Ibanez, 2007, p. 171). Samuels (p. 199) stressed the value of the technique for "bridging the culturally distinct worlds of the researcher and the researched." In our case, the bridged worlds were those of the younger participants and the older researchers, and also the worlds of adolescents who were highly familiar with the daily challenges of living with chronic health conditions and the worlds of the interviewers who had less familiarity with this. Unlike photovoice, photo-elicitation approaches tend to emphasize images as a means of accumulating rich verbal data, which then tends to be prioritized over the visual photographs themselves.

Our research design for the development of the visual storytelling approach within a study of adolescents developing practices of chronic disease self-management was guided by six methodological elements; that is, six elements

that fit with our particular inquirer stance as promoters of youth-centered research. We wanted our approach to (a) focus on young people as social actors; (b) seek research information directly from young people; (c) promote depth of communication by extending the established technique of in-depth interviewing; (d) appeal to young people with an activity they would like to take part in; (e) be enabling and empowering to young people; and (f) promote young people's voices being heard throughout the research process. A visual approach to data collection had the potential to accommodate these goals. By combining elements of both photovoice and photo elicitation we were able to avoid prioritizing either visual or verbal information in the broader study, and to view both as equally valuable data.

In this article we describe the visual storytelling method and outline the benefits and challenges of the approach as manifested in our broader research project focusing on adolescents' developing practices of self-management. The old adage, "If only I had known then what I know now," is highly pertinent in relation to our experiences with this research approach. As such, we focus here on issues of feasibility, with the goal of sharing our knowledge of what it takes to successfully employ this visual approach to data collection.

The main aim of our broader research study was to hear adolescents' and parents' perspectives on issues relating to young people's developing practices of chronic disease self-management. However, we also recognized that we had an important opportunity to obtain information and feedback about how the visual approach was received and experienced by participants as part of the broader study. The overall self-management research design offered us a valuable opportunity to look at the feasibility of a new research method and consider its utility for health research with young people.

Methods

Participants and Recruitment

Ethics approval was obtained from the Royal Children's Hospital (Melbourne) Human Research Ethics Committee. Adolescents aged 10 to 18 years with asthma, diabetes, or cystic fibrosis were eligible to participate, together with a parent. To support investigation of adolescents' developing practices of self-management, selection criteria for young people included a diversity in the length of time since diagnosis, and consequently diversity in the duration of chronicity experienced by participants. For example, cystic fibrosis is a genetic condition that is now generally identified at or close to birth. The diagnosis of asthma or diabetes might occur at any point through

childhood or adolescence. Adolescents ($n = 34$) and parents ($n = 34$) were recruited in clinic waiting rooms at the same time.

Patients at the hospital commonly attend review appointments with at least one parent/guardian and as such, pairs are highly likely to be sitting together in clinic waiting rooms. Additionally, research participation for people under the age of 18 years (a) usually requires parental consent, and (b) usually requires that the parent be consulted prior to researchers asking people under 18 years if they would be interested in participating in research. For these reasons it was a necessary starting point for our recruitment approaches to involve both adolescents and parents simultaneously. We were also aiming, where possible, to recruit dyadic pairs to gain different perspectives on the understanding and practices of chronic condition self-management within any one household. The limited number of research articles published about chronic disease self-management in adolescence state clearly that parental involvement continues well into the late teenage years, and even into early adulthood (Anthony et al., 2009). A central preoccupation of our broader research inquiry was therefore to increase understandings about the shared and interconnected roles of parents and adolescents in self-management. This required an emphasis on recruiting parent and adolescent pairs.

Throughout recruitment, research staff were keenly aware of the importance of giving adolescents the opportunity to opt out of participation. A separate "young person consent form" was used as a technique for increasing adolescents' understanding of what participation entailed and for increasing their options for declining involvement. Recruitment was completed by the first and second authors, who are experienced in research with minors (Duncan, Drew, & Sawyer, 2009). As such, they were attuned to the potential for parental coercion during recruitment, and would not have proceeded with recruitment if they felt that this was occurring.

Within this article, the terms *adolescent*, *youth*, and *young people* are used interchangeably. As the study sample consisted of 10- to 18-year-olds, we commonly use the term *adolescent* when referring to specific aspects of the study, and the term *young people* for more general aspects.

Data Collection

Young people were provided with a 36-exposure film-based disposable camera and asked to create a series of photographs to show (a) what it was like to live with an ongoing health condition and (b) the sorts of things they might do to take care of their health. We made a deliberate choice to request such a specific focus from participants

because time and budget constraints meant that we had only one opportunity for participants to create images, and one opportunity to talk in depth with them about their experiences and understandings of chronic disease self-management. The first author was simultaneously involved in another chronic-illness visual research project exploring young people's experiences with social and educational connectivity (White, Drew, & Hay, 2009). That project had a longitudinal design and afforded multiple and extended opportunities for image creation and interview discussion. In that project a deliberate choice was made to ask participants to begin with a more general visual story of their lives, knowing there was time to pursue a tighter research focus at a later stage if necessary (Guillemin & Drew, 2010). Regardless of the focused nature of the instructions for our self-management-related visual tasks, adolescents highlighted both illness-related experiences and other aspects of their lives. These images readily linked to both positive and challenging elements of their experiences.

In this self-management study, cameras were usually provided to young participants at the time of recruitment following completion of some preliminary questionnaires (separately) by both parents and adolescents. There were occasions when there was not enough time for initial questionnaires to be completed during recruitment; therefore, cameras were sometimes mailed to young people at their homes after completed questionnaires had been returned to the research staff.

Although parents were not recruited to participate in the photographic component of the project, the processes of recruitment meant that they were familiar with the research task that young people had agreed to complete. Additionally, the completion of both adolescent and parent interviews was tied to the completion of the adolescent's visual task. Follow-up processes undertaken by research staff to achieve return of the camera and scheduling of the interviews meant that researchers were repeatedly in phone contact with both adolescent and parent participants. We were careful to achieve an appropriate balance between gently requesting that the young person pay attention to the task and not coercing them to do something they did not want to do. Indeed, there were times when we encouraged individual adolescents not to bother taking photos, and to send back the camera without doing anything further if we felt the young person had lost interest in the task. We also made it clear to parents that the photographic task was completely voluntary and that the young person should only do it if they wanted to. It was assumed that parents would have a role in "reminding" their respective son or daughter about what he or she had agreed to do. This would be the case automatically in many households that include 10- to 18-year-old youth,

whether the reminder related to homework, household chores, getting to sporting or social events, or even attending scheduled appointments. While implicitly relying on parents' capacities to help adolescents "manage" their commitments, we also made it very clear to parents that it was not their responsibility to ensure the photographic task was completed, or to assist their children in developing ideas for photographs.

Adolescents were not told specifically how many photos to take, but they were informed that they could have an additional camera if they found they wanted to take more than 36 photographs. A written information sheet provided with each camera stressed that the adolescent would be the first to view their developed images, and that they would have an opportunity at the start of the interview to remove any images they did not want the researcher to see. This process was established to promote return of the cameras even if participants felt the cameras contained images they did not want to share. Few participants removed photographs.

Our aim was for the image making to be completed and camera returned within 2 to 4 weeks. Occasionally cameras were returned more quickly, but it commonly took longer. The images created by each adolescent formed the basis of individual interviews, which took place as soon as possible following receipt of the camera and development of the photographs. Separate but simultaneous interviews were conducted with adolescents and parents. According to family preference, most interviews took place in participants' homes; a few took place in nonclinical areas of the hospital. Parents did not view the photographs as part of their interviews.

Completion of simultaneous but separate interviews required a team of at least 2 interviewers. The challenges of coordinating the time availability of adolescents, parents, and research staff meant that we extended our interviewing team to three people to increase our flexibility with scheduling. Interviews with adolescents (34) were completed over the course of the project by the first and second authors. Interviewers had a list of topic areas and prompts to help shape the interview discussion; however, interviews were characterized by an intertwining of participant-led conversation about the photographs and associated experiences, and responses to more direct questioning from the interviewer. Through the course of the interviews, young people explained why they had made their images, how they were taken, and what they intended to convey within individual images or in their image series as a whole. At times young people said that a parent, friend, or sibling had contributed to the decision making about or taking of a particular photo. This did not detract from the overall value and validity of the young people's photographs as data, because they were always clear

about which photos were important to them as individuals and why, thus articulating a vivid and personally meaningful visual story (see also Guillemin & Drew, 2010).

Interviews with parents (34) were completed over the course of the project by the second author and another research assistant. As in interviews with young people, interviewers had a list of topic areas and prompts to help shape the interview discussion with parents, but participants were free to take a lead in the discussion according to their level of comfort in doing so.

For the purposes of exploring the utility of the method, toward the end of each interview with adolescents and parents interviewers specifically sought information about whether the camera had influenced young people's decision to participate, what benefits they might have experienced as a result of creating their visual story, and what challenges or harms they might have experienced as a result of creating their visual story. Parents were included in this assessment of the approach because of their involvement in the overall recruitment process and because of their familiarity with the visual research task as outlined above. We were not necessarily looking for concordance in assessment views expressed by parents and young people, knowing that young people and parents often prioritize and interpret aspects of life experiences differently.

Analysis

All interviews were audio-recorded and transcribed verbatim. Transcripts were imported into NVivo 8 qualitative data analysis software throughout the data collection period for data management and coding. The first author had primary responsibility for computer-assisted coding and establishment of themes (Rice & Ezzy, 2000). General principles of thematic analysis were applied (Boyatzis, 1988; Braun & Clarke, 2006). Use of these principles was also informed by a constructivist perspective on grounded theory methodology (Charmaz, 2007).

Data from adolescents and parents that related to the visual storytelling approach were broken into smaller units through open coding and then put back together in new ways through memoing (Welsh, 2002) and axial coding. This process enabled prominent themes, sub-themes, and the relationships between them to be identified and elaborated upon. Two additional steps of coding also informed the emergence of key themes; data were (a) scrutinized to explore the presence of commonality or disparity between the responses of a particular young person and his or her parent, and (b) scrutinized to establish whether participants' opinions about the approach might be related to the young person's age (i.e., related to developmental issues in self-expression), gender, or type of health condition.

Consistent with grounded theory methodology (Strauss & Corbin, 1990), data analysis was also ongoing throughout data collection. Postinterview debriefing discussions, postinterview reflexive journaling, and regular project meetings provided multiple avenues for authors to participate in discussion and consolidation of analysis. Conversations during project meetings about the substantiation of each theme and subtheme provided additional avenues for team-wide contributions to analysis.

Results and Discussion

Distinct benefits were associated with the visual storytelling approach, although a range of challenges were also apparent. The results and discussion are presented in four sections to describe the key issues during (a) recruitment, (b) image making, (c) interviews with young people, and (d) dissemination of findings.

Key Issues During Recruitment

We had anticipated that interest around the disposable cameras would positively influence recruitment. This was not necessarily the case, as only a modest recruitment rate was achieved. Of 80 eligible participant pairs (young person plus parent) who were approached, 49 (61%) agreed to participate, of which 34 pairs (42.5%) completed all aspects of the study. Very few young people expressed that the camera markedly influenced their decision to participate. Indeed, 16 adolescents indicated outright that the camera component had little effect, stating that they would have become involved anyway; yet the camera acted as an enticement in recruiting others. It also commonly increased positive feelings about the project at the time of recruitment. One young participant reported feeling excited by the approach, saying, "It's definitely a different idea," and another reported that it made the study seem "better than just the normal survey." The positive influence of the camera appeared greatest with girls regardless of age, and with boys up to the age of 15 years. Figure 1 shows key themes from young people's comments about the influence of the camera on recruitment. Parents commonly stated that their son or daughter initially saw the camera as an enticement, something that was "fun" or "a bit different" from filling out surveys or trialing new medications; however, many parents stated that the image-making task became more problematic later on.

Key Issues During Image Making

"I actually enjoyed doing that." The task of creating a visual story was described by 1 in 3 participants as being fun. Furthermore, about half of the participants commented

Major Influence on Participation

Yeah, that was probably why I chose it, 'cause you got to do stuff with the camera. That's probably most of the reason why I chose, yes.

Yeah, I thought it would be really interesting, actually. I thought it was a good idea.

Yeah, [it influenced my decision to take part], I thought it'd be fun, the camera part.

Little Impact on Participation

I wouldn't be as much like, excited without the camera but I still would have done it.

Even if there weren't any camera I would still go for it because it's to help others.

I think I would have probably done it anyway.

Sounded Like an Interesting Activity

I was like, this is interesting, I'll try it. . . . I probably would have done it anyway. But it was appealing.

[The camera component] actually kind of intrigued me, 'cause I'd never had anything like that before, so I thought it might be, it might be something different to do. [If the camera hadn't been part of the project], I probably would've [taken part], but it was definitely an appealing kind of thing to do 'cause we've been surveyed, over 18 years we've been surveyed a lot by people, so this is something different, which is good.

I reckon it sounded pretty fun, so I thought, "Yeah, let's do that."

Figure 1. Influence of the camera on recruitment

that an unexpected benefit of participating in the image-making process was that it fostered personal reflection (that they viewed positively) about living with their chronic health condition. One participant said, "It taught me a little bit more about who I am." This type of feedback came from young people across the range of ages and conditions. Several young people indicated that this personal reflection had the potential to influence their self-management activities, such as in relation to adherence with medication, seeking health information, and communication strategies and skills. Figure 2 illustrates benefits of visual storytelling highlighted by the young people.

Difficulties creating enough images and knowing what to photograph. Although some participants easily completed the task of creating a visual story of what it is like to live with a chronic health condition, about 75% required some degree of "coaching" from project staff and parents to complete the task. In certain cases, the challenge was as simple as not being able to think of enough images to use the length of film in the camera:

Yeah, it was like, got to finish the film . . . 'cause I had it for ages and I think someone rang up and

like, "Oh, can we have the camera?" And I'm, "Oh God, I'll have to finish it." . . . Finishing the whole film—I could probably do ten pictures easily, but like a whole film was harder.

About half of the adolescents expressed difficulty knowing what to photograph. For several reasons it is not surprising that young people found it difficult to represent their illness experiences photographically. First, asking young people to use cameras to document anything related to personal challenges confronts our cultural habit of using cameras to generate images of celebrations and positive experiences (Chalfen, 1987). Second, as illustrated by the participant quotes in Figure 2, thinking deeply about what it is like to live with a chronic health condition is not something adolescents often do spontaneously. Third, thinking about these issues requires some degree of abstract thinking and self-reflection, which might be more difficult for younger adolescents given their level of cognitive maturation.

About 25% of the young people struggled to photograph anything. One participant, who had initially been enthusiastic about image making, ended up completing the interview without taking any photographs. In spite of negotiating early to use his own digital camera, that participant expressed a growing reluctance to create images. His explanation is presented in Figure 3. This example highlights that for some, a film-based disposable camera might seem an out-of-date medium with technological limitations. We argue that the real value of this approach is not in the specific medium of digital- or film-based photography, but rather in the task required by participants prior to the interview. We argue that young people's engagement with the content of inquiry through photography was a critical aspect that facilitated communication during the interview. Even though the one young man did not create any images, he nevertheless was highly engaged in thinking about how he might adequately represent his experiences and ideas, which facilitated later discussions.

Forethought and planning is required. One of the most practical challenges around employing this research method was the amount of forethought, planning, and coordination required by adolescents. Not only did they have to remember that the task needed completing; they had to think about what to photograph, to plan ahead and coordinate aspects of location and photo content. At the most basic level they needed to ensure they had the camera with them so they could use it at opportune moments. This presented challenges for adolescents as well as for parents. Parents (primarily mothers) reported that they commonly found themselves reiterating instructions and even nagging their child to get the task completed. On rare occasions it was indicated that the image-making task "became a chore." About half of the parents discussed being partially

Creating the Visual Story Was Fun

Yeah, I thought it was fun. 'Cause, um, just—I like taking photos.

Well, I actually enjoyed doing that . . . everyone wants to take photos.

It was pretty fun 'cause you got to take pictures. I like taking and clicking. It's fun for me.

Fostering Reflection

Well it actually made me think about my asthma and how it affected my life . . . it's made me think about things I wouldn't normally think about, and yeah, interesting experience.

I had to take the pictures and it was about how CF [cystic fibrosis] affected me, so I was thinking about things and I found it a bit hard maybe because I don't usually think about that, and I was sort of like—it was, it was a bit like reflecting back on what affects my life with CF.

It made me realize that I have to rely on a few things like a lot of people wouldn't have to . . . I have to take a lot more stuff to school and like make sure everything's fine during the day. So it's a bit harder. It just made me realize that—how much different it really is. Like I thought it was pretty much like the same as the normal person, but it's a lot different.

Self-Management

It's reminded me that I need to have my Seretide [asthma medication] more often.

I don't know how to explain it—Yeah, it got me to think about it [cystic fibrosis] more and think of new things and ask more questions and stuff . . . I reckon it was a good thing 'cause now I know more about it and I'd like to know more about it.

Probably being more honest than what I actually have been in the past. Like I mean more open, open to talk than what I was maybe say six months ago.

Facilitating Expression and Communication

It makes it clearer in your head sort of 'cause you know it's all up there, but it's all sort of garbled you know in here, whereas looking at the pictures saying that looks into that, that represents that, sort of helps you understand what you are thinking yourself.

I think you should use it in the future 'cause it makes, makes people think about it and like it's not, "Oh yeah, all I have to do is only answer a few questions" and stuff. Like they—and you get to see what—what their life is actually like. What, what it involves and like what they have to take and it's—I reckon it's good, good that you, you've made a camera kind of thing.

It's a good idea 'cause it's really like, if you find it hard to say like, like for some students, kids, they may be more creative, more like imagery based. Like me—me personally I'm more picture—like I remember things better by pictures.

Well at first when I heard about it I'm thinking like, "Wow, I'm not going to be able to do this. It's going to be ridiculous, you know, taking photos. How's this going to be helpful?" I couldn't, off the top of my head I'm thinking, "What the hell am I going to take photos of?" But after a while, you know, reading through the sheets that came with it and, you know it was a bit of fun I guess. You know, taking photos like that. Like I said, it was a good memory kind of job, sort of think of things to talk about and so yeah, it wasn't too bad.

Figure 2. Benefits of visual storytelling

involved in determining what would be photographed. Much less frequently, parents stated that they were fully responsible for creating certain images. These issues added to the challenge of analyzing the images as part of the broader self-management study, in terms of considering whose story was being told at a particular time. In a number of cases, parents perceived the image-making task as more difficult for their son or daughter than did the young person. For example, one mother reported that for her daughter, the image-making task was "a drag." She went on to note that she (the mother) "was probably more excited about it than what she [the daughter] was." In contrast, her daughter described making the visual story as "fun," especially "having me in the photos."

Representing a "normal kid" and a "normal life." An important challenge of self-representation and image

making was highlighted by parents of young people with diabetes or cystic fibrosis, who often raised the issue of their son or daughter being reluctant to be seen as anything other than a "normal kid"; this appeared to be less of an issue for young people with asthma. Indeed, some parents and young people talked positively about increased awareness and an absence of stigma associated with asthma. This desire by adolescents to present themselves as normal is both a feature of the dominant socio-cultural discourses and storylines available for articulating illness experiences and a feature of adolescent development (Drew, 2005; Kroger, 2004). It also appears to serve as a coping strategy. Both of these aspects were interwoven within young people's attempts to provide photographic illustrations of themselves and their lives in relation to the management of ongoing health issues, and

During initial recruitment, a 17-year-old with diabetes negotiated to use his own digital camera to create his visual narrative because he felt that a more sophisticated medium might aid his production of satisfactory images. Nevertheless, he still struggled to illustrate the complexity of what he wanted to convey.

After viewing some artistically created, diabetes-related photographic images on the Internet, he became concerned about his capacity to produce the type of images he wanted to produce: "I just wasn't sure how to express it. Because I wanted it to be—I just didn't think . . . it wouldn't be a true sort of reflection."

The young man expressed a desire to accurately represent what he saw as the repetitive and time-related, ongoing nature of diabetes. He was not convinced he could achieve this just by using a disposable camera or producing a straight digital photo without enhancing the image and artistically manipulating the final image.

Although he struggled to resolve his concerns about adequately representing complex conceptualizations in simple snapshots, similar themes were represented by another young man with diabetes via his disposable camera. This other young man presented an image of a large pile of used syringes (Photo 1), as well as an image of a clock (Photo 2), and a celebratory altar that his mother had set up to mark the 1,000th syringe for his insulin injections (Photo 3). The altar was made spontaneously by his mother—not specifically in relation to the image-making component of the research.



Photo 1: Repetition

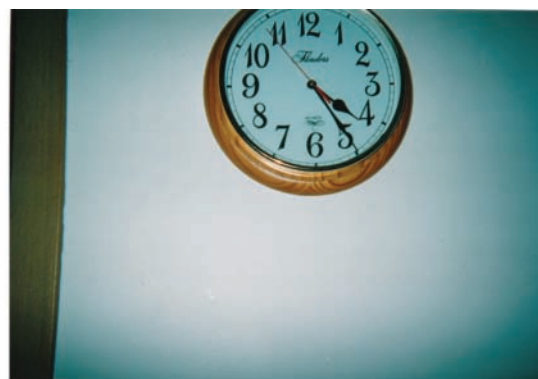


Photo 2: Time related



Photo 3: Ongoing nature of diabetes

Figure 3. Trials and triumphs of visual representation

this appears to have contributed to the challenges encountered by the young people in determining and knowing what to photograph.

The quote in Figure 4 highlights the significant emotional elements that relate to the task of creating a visual story of illness experience, which might otherwise be

conceived by some as a simple request for a few photographs. The quote also draws attention to the issue that many emotionally laden and difficult topics are left unspoken within families in which someone has a chronic illness—even within the context of close and supportive family relationships (Roderíguez et al., 2004).

She didn't know what [photos] to take. She's not often—I don't think she likes to be sentimental. . . . When you emotionally challenge [my daughter] she doesn't like that because she says, "Well, it's not important." So take photos of what? She doesn't know how she feels about her CF [cystic fibrosis]. I don't think she does. . . . She didn't like it [taking the photos]. I had these great suggestions. I'd say, "Get your enzymes and make flowers out of it." She said, "Oh, Mum, that's just stupid." I had all these great ideas. She just didn't—and then she's going, "I don't know what to take." So I talked to Rony [the researcher] and I said, "Rony just wonders, 'How does CF impact on you.'" She doesn't like to share that. The physio side, she doesn't want to share that side because she still knows it's not—she's isolated. No one likes to feel they're so different, and she doesn't either. . . . I don't know why she, she doesn't open up sometimes with me. So it's very rare that we'll have a conversation. Now and then she will really tell me, but rarely because she knows it breaks my heart. . . . She knows that if she opens up emotionally to me, I'd be a mess. So that's why we have this, "Let's just keep it not too emotional," because then we'll all just break down and be a mess, and we have to survive in this world. (Mother of a girl with cystic fibrosis)

Figure 4. The challenge of self-presentation and emotion management

Key Issues During Interviews With Adolescents

Notwithstanding these challenges, the creation and presentation of photographs as a central feature of the research encounter served to empower young people. It increased their control in determining the direction of their early storytelling (visually), and provided a powerful avenue for increasing their influence over the course of the research interview (verbally). The presence of a prop during the interview also reduced the pressure of verbal interaction, as previously reported (Darlington & Scott, 2003). Overall, it appeared that the visual storytelling technique served to facilitate rapport, break down age- and status-related hierarchical dynamics, and help generate rich interview discussions between adolescents and older researchers. It seems that many of the participants found involvement in this visual storytelling research project a rewarding experience. None of the adolescents articulated their participation as harmful in any way, nor did parents.

Visual storytelling extended the scope of standard qualitative interviews with young people by making visible and drawing into the conversation elements of the young people's lives and experiences which otherwise might not have been discussed. For example, one young man provided an image of a packet of cigarettes resting on the kitchen bench of his family home. This image prompted discussion about his father's practice of sometimes smoking inside the house, which the adolescent described as exacerbating his asthma symptoms. Outlining how the behavior of a parent impacts on well-being is

a difficult topic for a young person to broach. Through visual storytelling, the young man was able to easily raise and then expand on this sensitive topic. It was not otherwise mentioned in the interview.

A central motivation for developing the visual storytelling approach was to establish a method that was accessible for young people and fostered communication of sensitive and complex issues between younger participants and older researchers. Participants stated that the overall approach helped them to articulate difficult conceptualizations, aiding them in expression and communication, and helping them remember their own issues during the interview (see Figure 2). Hill (1997, p. 180) described the challenge of maximizing "children's ability to express themselves at the point of data-gathering; enhancing their willingness to communicate and the richness of the findings." Visual storytelling clearly met that challenge. Central to the success of the technique was the work done by young people prior to interview of conceptualizing expression of their experiences. We argue that this enabled them to more easily articulate, during the interview, aspects that they previously might not have thought about articulating.

Key Issues During Dissemination of Findings

We have found that visual storytelling extends the scope of communication at conferences and seminars. The emphasis within the photovoice methodology on exhibiting participants' images to capitalize on their power as a medium for communicating issues and promoting change has been borne out through our experiences of research presentations. In presenting the images, we as researchers become less of a conduit between raw data and final interpretations because audience members can quickly become engaged in viewing, assessing, and analyzing the data themselves. This illustrates success in relation to our goal of wanting the voices and perspectives of young people to be heard throughout the research process and dissemination of findings.

Conclusions

The visual storytelling approach is valuable as a youth-centered approach. It engages adolescents in reflection about their experiences prior to the research interview, which facilitates their expression and communication during the interview. Because of their degree of life experience and maturing cognitive development, young people are still developing the skills and capacities to readily consider and articulate complex understandings. Visual storytelling can help promote reflection and communication about issues that can be difficult to conceptualize and express, especially for young participants.

In providing cameras to the young people, a clear message was sent that we wanted them to be in charge of generating and shaping discussion in the research encounter. We think this approach also demonstrated that they had important perspectives to share, and that we were interested in understanding their experiences. By enabling young participants to highlight the areas of greatest importance to them, we deliberately increased their influence on the research process and reduced our reliance on researcher-generated logic about which areas were important to focus upon. As a result of utilizing visual storytelling, we obtained rich data through which young people's voices and perspectives are heard loudly and clearly.

In spite of the many benefits, there were also several challenges associated with this visual approach, especially the time required for researchers. Much time was spent on the telephone coaching young people through difficulties associated with completing the task, pursuing cameras that were not returned, and reorganizing interview times that were dependent on completion of the image-making task and return of the camera in time for the film to be processed prior to the interview. This is consistent with a project with adults, in which it was also found that participants required "encouragement from the research team to stay on task" (Baker & Wang, 2006, p. 1410).

There are two things that we are likely to do differently when using this approach in the future. First, we would be more prepared for the data collection stage to take longer than interview-only research. Second, we would build into the process a weekly phone call, mobile phone text message, or email contact with young people while they had a camera to proactively attend to the "coaching" aspects of the visual approach, and to reduce the need for parental input and monitoring in the completion process. Beyond these minor adjustments, it is our position that researchers will have to negotiate the challenges we have highlighted as inherent to the approach to get the benefits of associated rich and detailed discussions with young people.

Our exploration of the feasibility and utility of visual storytelling as a research approach has some limitations. First, the perspectives obtained were from participants who completed the project. Nothing is known of the opinions and experiences of the 7 pairs in which the young person received the disposable camera but did not complete the interview. Second, there was no comparison group in which interviews were conducted without the camera component. Although we are confident that the visual component enriched the data we collected, we lack comparative data to support this claim. Finally, the researchers who asked for feedback about the visual storytelling methodology were the same researchers who recruited participants and conducted the in-depth interviews. It is therefore possible that

participants were less candid about the experience than they otherwise might have been had their feedback been anonymous.

In summary, this focus on the feasibility of our visual storytelling approach demonstrates the utility of the technique and illustrates that the method has much to offer in terms of fostering our understanding of the lived experiences of adolescents with chronic health conditions. It also has much to offer researchers who are looking for ways to engage young people in research settings more generally. In spite of the challenges encountered, we would certainly use this approach again.

Acknowledgments

We gratefully acknowledge the valuable contribution made to this study by Jan Hodgson as research support staff during data collection.

Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research and/or authorship of this article: Funding support is gratefully acknowledged from the Invergowie Foundation and the Windermere Foundation (fellowship support for Sarah Drew), the National Health and Medical Research Council (fellowship support for Rony Duncan), the National Government (Asthma Targeted Intervention Grant), Kodak Australia Pty Ltd, FujiFilm Australia Pty Ltd, and the Murdoch Childrens Research Institute.

References

- Anthony, S. J., Kaufman, M., Drabble, A., Seifert-Hansen, M., Dipchand, A. I., & Martin, K. (2009). Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *American Journal of Transplantation*, 9, 614-619. doi:10.1111/j.1600-6143.2008.02515.x
- Baker, J., & Weller, S. (2003). "Is it fun?" Developing children centered research methods. *International Journal of Sociology and Social Policy*, 23, 33-58. doi:10.1108/01443330310790435
- Baker, T., & Wang, C. C. (2006). Photovoice: Use of a participatory action research method to explore the chronic pain experience in older adults. *Qualitative Health Research*, 16, 1405-1441. doi:10.1177/1049732306294118
- Bolton, A., Pole, C., & Mizen, P. (2001). Picture this: Researching child workers. *Sociology*, 35, 501-518. doi:10.1017/S0038038501000244
- Boyatzis, R. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101. doi:10.1191/1478088706qp063oa
- Carlson, E. D., Engebretson, J., & Chamberlain, R. M. (2006). Photovoice as a social process of critical consciousness. *Qualitative Health Research*, 16, 836-852. doi:10.1177/1049732306287525
- Chalfen, R. (1987). *Snapshot: Versions of life*. Bowling Green, OH: Bowling Green State University Popular Press.
- Charmaz, K. (2007). Grounded theory. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 81-110). London: Sage.
- Clark, C. (1999). The autodrive interview: A photographic viewfinder into children's experiences. *Visual Sociology*, 14, 39-50. doi:10.1080/14725869908583801
- Clark-Ibanez, M. (2007). Inner-city children in sharper focus: Sociology of childhood and photo-elicitation interviews. In G. C. Stanczak (Ed.), *Visual research methods: Image, society and representation* (pp. 167-195). London: Sage.
- Collier, J. (1967). *Visual anthropology: Photography as a research method*. Beverly Hills, CA: Sage.
- Cosaro, W. A. (2005). *The sociology of childhood* (2nd ed.). Thousand Oaks, CA: Pine Forge Press.
- Darlington, Y., & Scott, D. (2003). *Qualitative research in practice: Stories from the field*. Crows Nest, NSW, Australia: Allen and Unwin.
- Dresnick, M. (2006). Draw-and-tell conversations with children about fear. *Qualitative Health Research*, 16, 1414-1435. doi:10.1177/1049732306294127
- Drew, S. (2005). The delta factor: Storying survival and the disjuncture between public narratives and personal stories of life after cancer. *Storytelling, Self, Society*, 1, 76-102.
- Duncan, R. E., Drew, S. E., & Sawyer, S. M. (2009). Is my mum going to hear this? Methodological and ethical challenges in qualitative health research with young people. *Social Science and Medicine* 69, 1691-1699. doi:10.1016/j.socscimed.2009.09.001
- Fleury, J., Keller, C., & Perez, A. (2009). Exploring resources for physical activity in Hispanic women using photo elicitation. *Qualitative Health Research*, 19, 677-686. doi:10.1177/1049732309334471
- Guillemin, M., & Drew, S. (2010). Questions of process in participant-generated visual methodologies. *Visual Studies*, 25, 175-188.
- Haines, R. J., Poland, B. D., & Johnson, J. L. (2009). Becoming a "real" smoker: Cultural capital in young women's accounts of smoking and other substance use. *Sociology of Health and Illness*, 31, 66-80. doi:10.1111/j.1467-9566.2008.01119.x
- Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies*, 17, 13-26. doi:10.1080/14725860220137345
- Hill, M. (1997). Participatory research with children. *Child & Family Social Work*, 2, 171-183. doi:10.1046/j.1365-2206.1997.00056.x
- Kroger, J. (2004). *Identity in adolescence: The balance between self and other* (3rd ed.). New York: Routledge.
- Liebenberg, L. (2009). The visual image as discussion point: Increasing validity in boundary crossing research. *Qualitative Research*, 9, 441-467. doi:10.1177/1468794109337877
- Matthews, S. A. (2007). A window on the "new" sociology of childhood. *Sociological Compass*, 1, 322-334. doi:10.1111/j.1751-9020.2007.00001.x
- Mauthner, M. (1997). Methodological aspects of collecting data from children: Lessons from three research projects. *Child Sociology*, 11, 16-28. doi:10.1111/j.1099-0860.1997.tb00003.x
- Mayall, B. (2002). *Towards a sociology for childhood: Thinking from children's lives*. Philadelphia: Open University Press.
- Moss, T. (1999). Photovoice: Youth put their world on view. *Children FIRST: A Journal on Issues Affecting Children and Their Carers*, 3, 32-35.
- Oliffe, J. L., & Bottorff, J. L. (2007). Further than the eye can see? Photo elicitation and research with men. *Qualitative Health Research*, 17, 850-858. doi:10.1177/1049732306298756
- Packard, J. (2008). I'm gonna show you what it's really like out here: The power and limitations of participatory visual methods. *Visual Studies*, 23, 63-77. doi:10.1080/14725860801908544
- Patashnick, J. L., & Rich, M. (2005). Researching human experience: Video intervention/prevention assessment. *Australasian Journal of Information Systems*, 12, 103-111. Retrieved from <http://dl.acs.org.au/index.php/ajis/article/view/96/77>
- Pole, C., Mizen, P., & Bolton, A. (1999). Realising children's agency in research: Partners and participants? *International Journal of Social Research Methodology*, 2, 39-54. doi:10.1080/136455799295177
- Punch, S. (2002). Research with children: The same or different from research with adults? *Childhood*, 9, 321-341. doi:10.1177/0907568202009003005
- Radley, A., & Taylor, D. (2003). Remembering one's stay in hospital: A study in photography, recovery and forgetting. *Health*, 7, 129-159. doi:10.1177/1363459303007002872
- Rasmussen, K. (2004). Places for children—Children's places. *Childhood*, 11, 155-173. doi:10.1177/0907568204043053
- Rice, P. L., & Ezzy, D. (2000). *Qualitative research methods: A health focus*. Melbourne, Australia: Oxford University Press.
- Rodríguez, C. D., Rodríguez-Arias Palomo, J. L., Diz, J. C., Celis, M. V., Tuña, S. A., Larrea, M. O., . . . Varela, N. (2004). A preliminary report on multiple family discussion groups for patients with chronic medical illness and its repercussions in the management of the hemodialysis process. *Therapeutic Apheresis and Dialysis*, 8, 492-496. doi:10.1111/j.1774-9987.2004.00190.x
- Samuels, J. (2007). When words are not enough: Eliciting children's experiences of Buddhist monastic life through photographs. In G. C. Stanczak (Ed.), *Visual research methods: Image, society and representation* (pp. 197-224). London: Sage.

- Santelli, J. S., Rogers, A. S., Rosenfeld, W. D., DuRant, R. H., Dubler, N., Morreale, M., . . . Schissel, A. (2003). Guidelines for adolescent health research: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 33*, 396-409. doi:10.1016/j.jadohealth.2003.06.009
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. London: Sage.
- Streng, J. M., Rhodes, S., Ayala, G., Eng, E., Arceo, R., & Phipps, S. (2004). Realidad Latina: Latino adolescents, their school, and a university use photovoice to examine and address the influence of immigration. *Journal of Interprofessional Care, 18*, 403-415. doi:10.1080/13561820400011701
- Stuckey, H. L., & Tisdell, E. J. (2010). The role of creative expression in diabetes: An exploration into the meaning-making process. *Qualitative Health Research, 20*, 42-56. doi:10.1177/1049732309355286
- Tisdall, E. K. M., Davis, J. M., & Gallagher, M. (2009). *Researching with children and young people: Research design, methods and analysis*. London: Sage.
- Walker, R., Schratz, B., & Egg, P. (2008). Seeing beyond violence: Visual research applied to policy and practice. In P. Thomson (Ed.), *Doing visual research with children and young people* (pp. 164-174). London: Routledge.
- Wang, C., Cash, J., & Powers, L. (2000). Who knows the streets as well as the homeless? Promoting personal and community action through photovoice. *Health Promotion Practice, 1*, 81-89. doi:10.1177/152483990000100113
- Wang, C. C., Yi, W. K., Tao, Z. X., & Carovano, K. (1998). Photovoice as participatory health promotion strategy. *Health Promotion International, 13*, 75-86.
- Welsh, E. (2002). Dealing with data: Using NVivo in the qualitative data analysis process. *Forum: Qualitative Social Research, 3*, Art. 26. Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/865/1881>
- White, J., Drew, S., & Hay, T. (2009). Ethnography versus case study: Positioning research and researchers. *Qualitative Research Journal, 9*, 18-27. doi:10.3316/QRJ0901018
- White, R., & Wyn, J. (2004). *Youth and society: Exploring the social dynamics of youth experience*. South Melbourne, Vic, Australia: Oxford University Press.

Bios

Sarah E. Drew, PhD, is a postdoctoral research fellow at the Centre for Adolescent Health, The Royal Children's Hospital, Melbourne, and the Department of Paediatrics, The University of Melbourne, Melbourne, Australia.

Rony E. Duncan, PhD, is a National Health and Medical Research Council postdoctoral research fellow at the Centre for Adolescent Health, the Children's Bioethics Centre, and the Bruce Lefroy Centre for Genetic Health Research at the Murdoch Childrens Research Institute, Melbourne, Australia.

Susan M. Sawyer, MBBS, MD, FRACP, is director of the Centre for Adolescent Health, The Royal Children's Hospital, Melbourne, and the chair of adolescent health, Department of Pediatrics, The University of Melbourne, Melbourne, Australia.