Audio-video decision support for patients: the documentary genre as a basis for decision aids

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Abstract

Objective Decision support tools are increasingly using audio-visual materials. However, disagreement exists about the use of audio-visual materials as they may be subjective and biased.

Methods This is a literature review of the major texts for documentary film studies to extrapolate issues of objectivity and bias from film to decision support tools.

Results The key features of documentary films are that they attempt to portray real events and that the attempted reality is always filtered through the lens of the filmmaker. The same key features can be said of decision support tools that use audio-visual materials. Three concerns arising from documentary film studies as they apply to the use of audio-visual materials in decision support tools include whose perspective matters (stakeholder bias), how to choose among audio-visual materials (selection bias) and how to ensure objectivity (editorial bias).

Discussion Decision science needs to start a debate about how audio-visual materials are to be used in decision support tools. Simply because audio-visual materials may be subjective and open to bias does not mean that we should not use them.

Conclusion Methods need to be found to ensure consensus around balance and editorial control, such that audio-visual materials can be used.

Introduction

The use of patient decision support tools is increasing: many decision tools are now widely used in clinical settings.1,2 Decision tools are helpful in clinical situations where the evidence for the superiority of one treatment over another is not available, and the best choice depends on how a patient values the harms and benefits of the treatment options – in other words, situations of clinical equipoise.3 Their use has prompted efforts to standardize the development of these tools, such as the International Patient Decision Aids Standards (IPDAS) Collaboration.4 Although creating criteria for decision tools is an important goal, there is a danger that developing criteria may stifle innovation and the adoption of new ideas. Rigidly imposed standards would have the potential to create decision support tools that are over-engineered, too full
of detail, with excessive content, impractical to use and potentially lacking in innovative communication methods.

The IPDAS Collaboration did not achieve consensus about the use of narrative elements, such as those used in audio-visual materials. There was a reluctance to embrace these technologies because of a concern that narrative elements are too subjective and open to bias. Despite the fact that moving images and sounds are transforming the way we work, learn and play, the IPDAS criteria exclude the most widely used means of communication today, namely audio-visual materials. Although audio-visual materials are powerful and may be biased, it remains paradoxical that this ubiquitous means of communication is excluded from decision support standards designed for patients. In this article, we tackle these concerns and make suggestions regarding the use of audio-visual materials to support decision making based on narrative ideas discussed in the documentary film genre.

The field of documentary filmmaking has been tackling questions about subjectivity and bias for audio-visual materials for nearly 100 years. A rich dialectic surrounds the issues of truth and objectivity, manipulation and editing in documentary filmmaking, and there is much to be gleaned and applied to the world of decision science. Our aims are to explore debates from the documentary film tradition as they apply to using audio-visual materials in decision tools and then to apply these insights, focusing on how to assess different perspectives (stakeholder bias), how to choose among audio-visual materials (selection bias), and how to ensure an approximation to the concept of objectivity (editorial bias). For our purposes, we limit our discussion to documentary audio-visual materials that represent events and portray things as they happen. Thus, we will not consider other audio-visual materials commonly encountered in decision support tools such as animation, avatar representations, etc., topics which merit their own discussion.

Methods

Systematic approach

Our approach consisted of three steps. First, we examined standard texts in documentary film studies to define the documentary film genre and what they could potentially add to patient decision support. Second, we explored the problems that the use of audio-visual materials might pose and finally, we suggest solutions to these problems, as they apply in decision support sciences.

Results

What is a documentary film?

We list nine of the most commonly cited texts regarding the documentary film tradition (see Table 1). All are uniform in their approach to documentary film studies: they first outline what defines a documentary film and then explore the difficulties of capturing events using audio-visual materials.

Film historians have struggled to define the documentary film format. For the purposes of our article, we focus on two accepted aspects of documentary films that are relevant to decision science: the representation of events in documentary film and the relationship between documentary films and their viewers.

A fundamental feature of documentary films, in contradistinction to fiction films, is that the film images attempt to represent historical events and portray things as they happen (see Table 2). Sometimes this occurs in real time as the event occurs, or it may occur in a simulated setting where the intention is to portray things as they would normally occur. Whether it is a scene from a correctional institution’s mental health hospital for the criminally insane in Massachusetts, as seen in Frederick Wiseman’s classic documentary film *Titicut Follies*, or a public hospital ward in Cuba as seen in Michael Moore’s recent *Sicko*, the sights and sounds represented in the film images ‘bear an indexical relation to the historical world’. John Grierson,
one of the first documentary filmmakers, encapsulated this indexical relationship between film and the historical world by defining the documentary film as a ‘creative treatment of actuality’.6,8,9 Documentary films consist of places and sounds that represent a real place and time. A documentary film documents evidence and information from the world which legitimates its usage as a source of knowledge.6,10

It is precisely because of the indexical relationship between the images we see and hear and the historical world that documentary films have a unique relationship with viewers, the second aspect of documentary films that is of interest to decision science. ‘As viewers, we expect that what occurred in front of the camera has undergone little or no modification to be recorded on film or magnetic tape’.6 When viewing documentary films, the viewer assumes that the projected images remain identical to the actual images or events that ‘we could have witnessed in the historical world’.6 Because film images represent ‘reality’, we as viewers, perhaps naively, assume there is a pure, unmediated truth to the images that cannot be said of fiction film with its use of studio sets and special effects. This purity of objective reportage is one of the reasons why documentaries are separately indexed in catalogues or video stores apart from fiction films.9 Documentary filmmakers assert a belief that the images they present in films actually occurred or existed in the actual world.9

The unique relationship between documentary films and their viewers is similar to that between patients and decision support tools (see Table 2). Patients expect that the information and material presented in decision support tools are ‘true’ and unmediated. It is not a coincidence that great attention is given to issues of objectivity and bias in decision science, and remain some of the key features of quality criteria for decision support tools.4 But as with decision support tools, ‘truth’ and ‘objectivity’ remain an elusive goal in documentary films. Below, we explore the issues of truth and objectivity in documentary films and then the issues of objectivity and bias in audio-visual materials for decision support tools.

Truth and objectivity in documentary film
Although film images may be of real places and events, they are representations, not actuality. As with the shadows emanating from the fire in

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Plato’s Allegory of the Cave, film images are ‘shadows’ of reality and can often differ from the historical record. In every shot of documentary film, there are myriad choices of colour, film stock, perspective, angle, sound, speed, placement and time. These choices are sometimes fortuitous and other times carefully crafted by the filmmaker. Such choices in documentaries can ‘provoke and encourage response, shape attitudes and assumptions’.

Consider the choice made by Wiseman in Titicut Follies to film a psychiatric ward using black and white film. Would the dreariness and institutional nature of an insane asylum have been conveyed in the same way if the saturated colours of Technicolor had been used? What appeared to be prima facie an objective account of the historical record can quickly become a contrivance. This manipulation is encapsulated in the following musing by the historian turned film critic, Arthur Schlesinger, Jr.:

Yet a moment’s reflection suggests that the line between the documentary and the fiction film is tenuous indeed. Both are artifacts; both are contrivances. Both are created by editing and selection. Both, wittingly or not, embody a viewpoint. The fact that one eschews and the other employs professional actors becomes in the end an economic detail. And the relation of any film to reality, depends, not on the amateur standing of its participants being filmed. 6 They also avoided artificial lighting, music external to the observed scene, re-enactments, voice-overs or tampering with the raw footage. The filmmaker is transformed into the proverbial ‘fly on the wall’ observing and recording events transpiring before the camera lens, as the events occur without interruption. In its most pure form, cinématographe verité attempts to become completely transparent ‘capturing people in action, and letting the viewer come to conclusions about them unaided by the implicit or explicit commentary’. 13 The cinématographe verité filmmaker aspires to invisibility.

The chief criticism of this style of documentary filmmaking is that it pretends to be something that it is not. Regardless of how small and unobtrusive a camera or film-crew might be, their mere presence results in an altered form of reality as persons being filmed react to the unnatural presence of the camera. Simply the awareness of being filmed suffices to distort reality into something quite different.

Beyond the problem of invisibility, however, there are additional reasons to hold suspect the claim of pure objectivity. Every documentary film has a perspective and point of view that originates and is structured by the filmmaker. No film can escape a perspective, and under the guise of objectivity or truth, filmmakers have smuggled in subtle and not-so-subtle slants on the subjects they represent. Consider the insight from Wiseman, one of the greatest living documentary filmmakers, regarding the objectivity of documentaries: ‘I don’t see how a film can be anything but subjective… They are not objective because someone else might make the film differently’. The current discourse surrounding documentary films breaks with traditional claims of ‘objectivity’ and ‘truth’ and instead emphasizes ‘the subjective identity of the
It would be difficult to describe Michael Moore’s documentary *Sicko* without reference to his sardonic wit displayed in his voice-over narrative or the intentionally chosen provocative scenes. The same subject matter would be treated entirely differently by another filmmaker. The documentary filmmaker, such as Moore, acts ‘explicitly as the filter through which the world enters discourse’ of the film’s subject. The final product – the documentary film – is moulded and shaped by the filmmaker. The proverbial ‘camera that never lies’ is simply a falsehood. Cameras do not deliver unmediated truth, ‘production means mediation’. In the final analysis, a documentary film is a view from one window on the world: it objectively records the filmmaker’s subjective experience of the world, ‘the filmmaker’s witness’.

**Discussion**

The key features of documentary films are that they attempt to portray real events and that the attempted reality is always filtered through the lens of the filmmaker. The same key features can be said of decision support tools that use audio-visual materials. Decision support tools incorporate audio-visual materials in an attempt to add a sense of verisimilitude of the clinical reality. Visual images of real events and real patients add credibility and veracity to what is being discussed. However, those visual images are always filtered through the lens of the creator of the decision support tool. Thus, the concerns outlined earlier that have and continue to preoccupy documentary filmmakers – truth vs. contrivance, honesty vs. manipulation – also present a dilemma to decision scientists who use audio-visual materials.

Below, we outline three concerns arising from documentary film studies as they apply to the use of audio-visual materials in decision support tools. These include how to assess different perspectives (stakeholder bias), how to choose among audio-visual materials (selection bias) and how to ensure an approximation to the concept of objectivity (editorial bias) (see Table 3.) Our intent is not to settle these matters but instead to generate a debate regarding audio-visual materials in decision science.

**Stakeholder bias**

A critical issue to explore before contemplating the content or objectivity of audio-visual materials to be used in decision support tools is who decides what content to use or whether the content is fair and impartial. Should clinicians and patients decide, or should policy makers be the judges? If the former, should they include professionals who consult with patients facing these decisions or professionals who develop decision support tools? Should the patients include those who have previously faced the decision, or those who might face the decision in the future? And what should the roles of patients’ families and policy makers be? The issue of which stakeholders decide is critical because each stakeholder will have their own biases reflected in their choice of audio-visual materials and whether the content is fair and impartial.

Likely, a commingling of the various stakeholders at different stages of development will be critical to minimizing the issues discussed below regarding what gets portrayed in the audio-visual materials (selection bias) and whether it is accurate (editorial bias). As we have described elsewhere, the perspectives of the various stakeholders should be sought during the early stages of development and then again after the decision support tool is developed. First, before the filming process begins, a concerted effort by the decision scientists should be placed on conducting focus groups of the various stakeholders for whom the decision support tool is intended. This will commonly include medical practitioners (physicians, nurses, social workers, etc.) along with patients and their families. It is vital to include medical professionals from a wide array of subspecialties as what each professional focuses on during the consultation process with the patient may centre on a different perspective. For instance, the oncologist who focuses on the risks and benefits of chemother-
apy for a patient with cancer may focus on audio-visual materials of a patient receiving chemotherapy. This perspective may be a completely different focus from the palliative care physician who centres on the goals of overall care and chooses audio-visual materials of a patient outside of the hospital and living at home.

However, what is important to medical practitioners may not be equally important to patients and their families who must share in the decision making. It is important to include a wide array of patients from different stages of disease trajectory: those who are at risk of facing the decision as well as patients who have already faced the decision. Distinct concerns are raised at different points in the disease trajectory. For example, patients in the early course of cancer may be more interested in scenes of what happens with the administration of chemotherapy, thus preferring audio-visual materials surrounding chemotherapy, while patients in the final stages are preoccupied with avoiding ‘bad deaths’, and thus opting for audio-visual perspectives towards the end of life. Including these perspectives, as well as the perspectives of policy makers who also determine the options and context of these decisions, is vital to seek at the preliminary stages of decision support tool development. And it is critical to return to the various stakeholders after the tool is developed.

We envision an iterative process of commenting and editing among the various stakeholders regarding what the content of the audio-visual materials ought to be and whether they are accurate. Developing a method that balances the needs of different stakeholders is a requirement in this field.

Selection bias

The choice of which audio-visual materials to integrate into decision support tools will necessarily be limiting. As is almost always the case, there is more footage of audio-visual materials than can be realistically used. Concerns regarding the length of decision support tools, technological constraints, and limits to user attention span bar the use of all the material often available. How do we decide which audio-visual content to use and which to leave on the cutting room floor? Alternatively, how does the decision scientist select certain sequences of scenes over others? How can the decision scientist be sure that all the audio-visual content needed to consider all the important aspects revolving around informed clinical decision making have been included within the decision support tool?

One means by which audio-visual materials should be selected for decision support tools is to include the perspectives of the various stakeholders involved in the decision making as well as the likely users. Medical professionals, patients, and families will all have different needs regarding what visual images may be needed to add a sense of authenticity to the decision-making context. What may be required to imagine the context in which clinical decisions are made is necessarily different for clinicians, patients, and families. Thus, a deliberative process in which all perspectives are entertained will minimize the dominance of any one perspective.

One example of the complexities involved in selecting audio-visual materials includes our own work creating video decision aids for end-of-life decision making in advanced cancer. After interviewing medical practitioners, patients with cancer and their families, we sought to understand what information and potential audio-visual materials would be important from both the provider’s perspective and the patient’s/family’s perspective. In our work, providers focused more on medical interventions like cardiopulmonary resuscitation (CPR) and ventilators that are available at the end of life, while patients and families focused on nursing and home care considerations at the end of life. The audio-visual materials incorporated into the final version of the end-of-life decision support tool included both medical interventions (CPR, ventilators, hospitalization, etc.) and nursing and home care (bathing, feeding, etc.). Additionally, close attention was given to include a racially and ethnically diverse group of audio-visual subjects to reflect the diversity of patients with cancer.
our stakeholders. For instance in the end-of-life context, studies have shown that various racial and ethnic groups prioritize different aspects of medical care at the end of life.\textsuperscript{20,21} Although in this instance we chose to integrate the audio-visual materials deemed to be important by the various stakeholders, there will be a limit to how much can be included without being tiresome to users. An iterative process of evaluation and comments by the various stakeholders is one means by which decision scientists can ensure that no single perspective dominates what a fully informed decision will entail.

### Editorial bias

As with documentary films, there perhaps is no greater concern in the use of audio-visual materials in decision support tools than in the objectivity of the final product. The myriad choices involved in filmmaking (angles, film stock, background sound, etc.) and the sophisticated computer editing tools at our disposal make objectivity daunting. The production of audio-visual materials is inherently an aesthetic endeavour, and no series of criteria or rules will negate this fact. Audio-visual materials are the equivalent of visual narratives, and as we do not deny that narratives have a perspective and point of view, we should not deny that audio-visual narratives do not have a point of view.\textsuperscript{22} However, there are ways of mitigating the influence of the developer on the objectivity of the audio-visual materials used in decision support tools.

To minimize one particular perspective, different teams of decision scientists should be encouraged to develop and produce decision support tools using audio-visual materials on the same decision-making topic. Having different teams tackle the same clinical issue may lead to different audio-visual sequences created and used. Comparing different versions of decision support tools which attempt to provide information for shared decision making may highlight challenges and biases not previously appreciated. This criterion addresses Wiseman’s concern about the objectivity of documentary film: ‘I don’t see how a film can be anything but subjective… They are not objective because someone else might make the film differently’.\textsuperscript{9}

Seeing how different decision scientists decide to use audio-visual materials assuages some of the concerns regarding objectivity.

But we should not solely encourage a variety of perspectives to be entertained from the decision scientist’s or medical profession’s perspective. Patients and their families should be encouraged to develop and create audio-visual materials that can be incorporated into decision support tools. Two examples of this innovation include adolescents with asthma creating visual narratives of their lives, and patients with quadriplegia filming their experiences with paralysis.

Michael Rich et al.\textsuperscript{23,24} have used this method to understand the perspective of adolescents with asthma. In an innovative study, Rich et al. provided camcorders and basic computer editing equipment to adolescents with asthma. Their mission was to create visual diaries of their lives, focusing on the experience of living with breathing exacerbations. The footage developed by the adolescents included life experiences that only a patient would understand: uncertainty in detecting triggers of asthma, fear of sudden death and limitations to what is possible in life. It is inconceivable to imagine a decision support tool that did not include such important information that can only be gleaned from the life of a patient.

Consider another example of patients creating audio-visual materials: Gretchen Berland’s riv-

| Table 3 Concerns regarding audio-visual materials for decision support tools |
|-----------------------------|-----------------------------|-----------------------------|
| Bias                        | Concern                     | Examples                    |
| Stakeholder bias            | Whose perspective matters   | Patient, medical professionals, family, policy maker |
| Selection bias              | How to choose among visual images | Hospital or home setting, medical procedures, interviews |
| Editorial bias              | How to ensure objectivity    | Patient, medical professionals, family, policy maker |

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eting documentary ‘Rolling’. In this film, three quadriplegics offer a multidimensional understanding to living life from a wheelchair. The non-quadriplegic viewer experiences life from a radically different perspective: from three feet above the ground. A ubiquitous sense of optimism, satisfaction and resilience quickly dispel the dire stereotypes of quadriplegics that all too often creep into analyses of a ‘life worth living’. Not to add these vital perspectives to discussions regarding decision making in quadriplegia overlooks an important dimension that is crucial to the decision-making process. Encouraging a multiplicity of efforts to develop and film sequences to be used in decision support tools should be encouraged to counter concerns of bias and inauthenticity.

**Conclusion**

The next generation of decision support tools will undoubtedly include audio-visual materials. These decision support tools hold the promise of presenting medical information to patients and their families in a format that will be more familiar, audio-visual materials. These decision support tools will not only give information with images, they will also address how patients construct their preferences. As the long debate within the tradition of documentary filmmaking exhibits, audio-visual materials present both a promise and a problem. The promise is that visual images will more easily and accurately inform our decisions; the problem is that they can also distort real events and real people as much as represent them.

It is vital for decision science to start a debate evaluating how audio-visual materials are to be used within decision support tools. We have outlined some of the salient concerns including stakeholder bias, selection bias and editorial bias. Simply because audio-visual materials may be subjective and open to bias does not mean that we should neglect them, instead we should embrace them and continue the debate to study them.

**Conflict of interest**

Dr. Barry receives salary support as president of the not-for profit (501[3]c) Foundation for Informed Medical Decision Making (http://www.fimdm.org), which develops content for patient education programmes including decision aids. The Foundation has an arrangement with a for-profit company, Health Dialog, to coproduce and market these programmes to health-care organizations.

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