Living Life, Come What May

A Review of

Gleason (2016)
by Clay Tweel (Director)

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Reviewed by

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What needs to be stated is that disability—while never wished for—may simply not be as wholly disastrous as imagined.

—Fine and Asch (1988, p. 11)

Steve Gleason, a former defensive back with the New Orleans Saints football team, is well known for blocking a punt in a 2006 game, an event that came to represent the team and city’s recovery from Hurricane Katrina. In 2011, at 34 years of age, he was diagnosed with amyotrophic lateral sclerosis (ALS), formerly and perhaps more familiarly known as Lou Gehrig’s disease. Weeks after the diagnosis, Gleason learns that his wife, Michel, is pregnant with their first child. This documentary, a certified hit at the Sundance Film Festival, initially chronicles Gleason’s decision to film a series of video journals addressed to his unborn child. In these video entries, Gleason looks directly into the camera and offers extemporaneous thoughts that are humorous and poignant—his goal, of course, is to impart some wisdom about life to his child, as he fears he will lose his ability to speak clearly before the child will be old enough to know and understand him.

As Gleason talks to his child, he also talks to us, the viewer; we, too, get to know this fun-loving, humorous, and generous person. He is the sort of fun-loving guy we all would like to know, probably because his thoughts are unscripted and his demeanor is open and appealing. Laughter and smiles are constants. Fairly quickly, we share his fears and joys, we come to know his love for friends and family, and we bear witness to the challenges and indignities ALS imposes on him and those around him. Still, there are many moments to smile and laugh.

We become curious: How does he—how do they—navigate this situation? And then the overarching theme emerges: Live life. Gleason continues to live his life—he travels, he tweets, he speaks, he competes as best he can in a couple athletic events, and he works to lead a normal life (albeit one of a beloved athletic celebrity whose health condition quickly becomes known far and wide) insofar as circumstances allow. He even seeks renewed understanding with his father, a somewhat ambivalent figure who appears at intervals throughout the documentary. Michel is always there, as cheerleader, advocate, partner, and
Inspiration or Inspiration Porn?

The good news: *Gleason* is not a maudlin, sappy, or a manipulative documentary. Fortunately, then, it is not like many of those treacley movies that were so popular in the 1970s and 1980s, where a popular person (often enough an athlete) is undone by some unexpected disease but teaches viewers how to appreciate each and every day, despite dying in the process. I do not believe—to borrow a term from disability culture—that this film is an example of *inspiration porn*. This term is invoked whenever a person or persons with a disability are seen as inspiring by others simply because they have and live with some disability (Young, 2012). Nondisabled observers will often consider disabled protagonists to be “brave,” for example, which is a form of objectification (e.g., “If that guy can continue to fight in the face of that crippling disease, then I should quit complaining about my petty problems and face them head on”). The real risk posed by inspiration porn is that observers will see deep meaning in clichés that are usually found on bumper stickers and refrigerator magnets (i.e., “Winners never quit and quitters never win”).

As the late lawyer and disability activist, Harriet McBryde Johnson (2005), trenchantly observed,

> Because the world sets people with conspicuous disabilities apart as different, we become objects of fascination, curiosity, and analysis. We are read as avatars of misfortune and misery, stock figures in melodramas about courage and determination. The world wants our lives to fit into a few rigid narrative templates: how I conquered disability (and others can conquer their Bad Things!), how I adjusted to disability (and a positive attitude can move mountains!), how disability made me wise (you can only
I never felt that Steve Gleason was being portrayed as especially brave or as an exemplary person, although the documentary does skate very close to the line between being inspiring and representing inspiration porn. To be sure and fair, he is inspiring, but only because he tries to be a good father and partner, one who works to help others with similar conditions because he happens to have a bully pulpit that allows him to do so. Thus, he is an atypical person with ALS, but he is also someone trying to live his life and do for others in the process, but not for any reward and certainly not for personal glory. Or, if there is a reward and a form of personal glory, it’s being a figure Rivers can look up to with informed understanding in the fullness of time.

Now What?

This is largely an educational film, which means educators should consider how best to leverage its use in the classroom. It would readily spark discussion in a seminar on disability issues or one taught in a Disability Studies Department (i.e., the inspiration porn angle). In a positive psychology class, the documentary could be used to explore the nature of happiness and the good life (if nothing else, it is clear that Steve Gleason led and leads a good life), as well as topics like resilience and psychosocial adjustment to disability. A human adjustment course would benefit from viewing and discussing the film in the context of health issues and their impact on the affected individual, as well as family and friends. In each of these cases, however, I would urge instructors to explain with care that disability, even in the case of ALS, is not the worst thing that could ever happen to a person (Fine & Asch, 1988; see also, Dunn, 2015, for a review). As Steve Gleason amply demonstrates to viewers of this film, whatever else it may be, disability is part of being human.

References


