

Chapter 5.4

Sharing Information about the Pain: Patient–Doctor Collaboration in Therapy and Research

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ABSTRACT

The chapter presents findings from recent studies that feature a model of doctor-patient collaboration called Video Intervention/Prevention Assessment (VIA), a research methodology that engages patient-participants in sharing their life stories on video, communicating their concerns and teaching their doctors what it means to live with a chronic illness. Patients are collaborators in creating a comprehensive understanding of illness that expands the medical community's definition of disease. This chapter focuses on visual narratives made by young patients with Cystic Fibrosis and Spina Bifida as they experience their transitions from pediatric to adult-oriented medicine care. Collaboration in research facilitates more effective ownership of and accountability for their illness, facilitating adherence to treatment plans and improved quality of life. Our chapter concludes with an evaluation of the pros and cons of VIA as a collaborative information methodology.

"I think that's really cool that someone actually takes the time to watch it [my videos] -- I respect your job a lot. The thing with doctors is they think they know everything." (Male participant with Spina Bifida)

INTRODUCTION

Although the professional practice of medicine has always been collaborative, in the sense that the doctor depends on information and cooperation from the patient, the doctor-patient relationship has traditionally been approached and experienced

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as paternalistic. Patients and doctors develop phenomenological constructions of each other, of disease, and of the illness experience by contributing information through a range of verbal and non-verbal communications, including medical and psychosocial histories, physical examinations, and laboratory evaluations. The rarely achieved ideal collaboration between patient and doctor uses ongoing open communication to seek similarities and address differences in these conditions, to find a common understanding of the illness, to share responsibility for treatment plans and outcomes. Patient-doctor interactions are marked by mutual requests for sharing information from two experts, the patient as owner and custodian of a particular illness and the doctor who possesses diagnostic, therapeutic, and prognostic knowledge of diseases (Cordella, 2004; Heritage & Maynard, 2006).

Current states of medical economics and informatics are exerting an impact on modes of collecting information that are fundamental to successful collaborations. Doctors obtain better anatomic and physiologic data, but have sacrificed rich psychological and socio-cultural information. The demise of the house call has dramatically shifted how doctors know their patients. The contexts of information-gathering are not part of the patients' worlds, but sterile clinical settings such as emergency rooms, clinics, hospital rooms, and doctors' offices. Office visits and hospital admissions, opportunities to observe the patient and the disease process are becoming shorter. The trend is clear. Technologically advanced testing both increases and improves anatomical imaging and physiological metrics.

In other ways, however, the quality of medical data is diminished as knowledge of illness-in-the-home-context is no longer available. Assessment of patient behavior and disease signs is now relegated to collapsed periods of time or replaced by medical tests that examine the structure and function of single organs, diminishing opportunities for learning the psychosocial and cultural information that define the whole patient. Because

patients suffer their disease processes in the context of their lives and their worlds in which they live, their illnesses cannot be fully understood and their quality of life cannot be effectively addressed without doctors learning about and responding to how their diseases are experienced by individual patients within the context of their lives.

Long seen by both patient and doctor as the passive supplicant, the patient has a great deal to contribute to a collaboration in diagnosis and healing, filling blind spots in the doctor's observational and diagnostic methods. Not only does the patient bring intimate knowledge and constant monitoring of her body, herself, and her life to the collaboration, but she can share and work with her rich experience with illness and wellness. Her personally realized knowledge of a particular illness, her theories of its origin, contagion, persistence, and the meaning of living with it -- what Arthur Kleinman has described as the "explanatory model" (Kleinman, 1988) -- are all important diagnostic evidence and potentially powerful therapeutic tools. How can we open channels of communication so that patients can express and doctors can hear this important information? We simply asked patients to teach their doctors about their lives with illness, their experience, concerns, and needs, implicitly and explicitly linking collaboration and communication.

To engage patients in a more equitable collaborative relationship with their clinicians, an innovative research methodology has been developed at the Center on Media and Child Health at Children's Hospital Boston. Video Intervention/Prevention Assessment (VIA) is a research methodology that asks patient-participants to use video technology to reveal their own medical conditions and communicate how they see themselves living with those conditions in their own physical and social environments. VIA is built on the assumption that patient-participants are collaborators who offer direct and intimate portrayals of their illness experiences, co-creating with their doctors a comprehen-

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