

Bridging the Divide

Using visual research methods to improve patient-provider understanding

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Introduction

Miscommunication between provider and patient still occurs, which can impact treatment and overall care of the patient.

Improving understanding and trust between provider and patient can therefore be seen as a critical component in the care of chronic illness.

Using a unique approach that lets patients create visual illness narratives to overcome this divide can enrich the understanding of what it means to live with a chronic illness like Cystic Fibrosis (CF) on an everyday basis.



Purpose

The idea of this project is to determine how much we can learn by using a visual research method called VIA (Video Intervention and Prevention Assessment) in working with CYSHCN.

Can the relationship between patient and provider be improved by integrating the gained knowledge from these video diaries into the care provided to the patient?

Methods

- Extended participant observation as part of the interdisciplinary team
- Analyzing the dynamics in the interdisciplinary team with a particular focus on knowledge sharing
- Experiencing the clinical encounter between providers and patients
- In-depth studying of the existing visual material
- Visiting the patient outside of the clinical setting to enrich view of social circumstances and compare to video diaries
- Interviews with providers of the interdisciplinary team
- Filming the interactions between patients and providers as well as the information sharing occurring during team meetings



"The divides in health care need to be bridged in order for effective treatment to proceed. [...] The solution is to discover a way to reconnect doctor to patient through a bridge of common understanding and shared ways of knowing disease. We need nothing less than a new philosophy of medical knowledge." (Rita Charon, 2006)

Findings



- The video diaries contain a large amount of information about adherence, self-image, the role of the illness, its impact on social relationships and children's goals.
- Collecting and analyzing this material can create new knowledge about the patient's everyday reality.
- Understanding more about the child's illness experience and integrating social aspects of their life into the medical care are particularly important when it comes to chronic illness.
- Trust and a more holistic view of the patient helps in building a partnership between provider and patient.
- Integrating the gained knowledge into the interdisciplinary team meeting can be seen as a valuable approach and can equip providers with necessary information that will help improve the communication with the patient.
- The video diaries can help share knowledge and a unique patient's perspective that other communication channels would not provide.

The Film

Part of this project is a film showing the functioning of the interdisciplinary team. The film also provides two different views on the chronically ill child:

1. The audience meets the child during a clinical encounter "as a patient".
2. A more personal insight into the child's life is provided by integrating the visual illness narratives created by the children themselves.

- ➔ Perception and concept of "patient" is being challenged in viewers
- ➔ Knowledge about living with CF is being shared



Outlook

The VIA project provides a valuable perspective to understanding more about the child/adolescent living with CF.

The interdisciplinary team and its focus on family-centered care support such an approach.

This method could be applied in other clinical settings that aim to enrich their knowledge about the patient's illness experience.

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