

School-Age Boys with FXS in Educational Settings: An Ethnographic Approach

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Overview

There is no lack of psychological studies and theories about Fragile X Syndrome. However very few studies investigate the actual classroom academic and social behavior and setting under which these students learn (see also Symons, et al. 2001).

This project investigates the following topics:

- What is everyday school life like for school-age boys with Fragile X Syndrome (FXS)?
- What do pupils with FXS do at school and how do they do it?
- How do the often described behavioral features („behavioral phenotype“) present themselves in everyday school life? Are there patterns for specific classroom behavior?

As simple as these questions might sound, it is difficult to evaluate them in a non-biased way. It seems that psychological as well as educational approaches both have very different objectives in their research. Psychologists utilize theories about genetic syndromes and their medical and genetic background regarding the etiology and behavioral phenotypes, whereas educators mainly consider the academic possibilities and degree of intellectual disability under which their students learn. They often consider etiological diagnoses as irrelevant.

The ethnographic approach of this study follows the actual performance of the students with FXS, uncoupled of the psychological and educational focus.

Methods

To investigate the daily routine of pupils with FXS at school in a systematic way, I adopted a qualitative research approach based on an *ethnographic participant observation methodology*.

The analysis and interpretation of field notes, drawing on *Grounded Theory* (Glaser & Strauss 2010), offers insights into the social interaction and “performance” of both pupils with FXS and their teachers. As simple as the research questions might sound, it is difficult to evaluate them in a non-biased way. It seems that psychological as well as educational approaches have different perspectives and aims. Psychologists utilize theories about genetic syndromes and their medical and genetic background regarding the etiology and behavioral phenotypes, whereas educators mainly consider the academic abilities and degree of intellectual disability of students and often consider etiological diagnoses as irrelevant.

Participant observation involved three individual boys with FXS (8, 10 and 12 years old) in their special education classrooms over a period of two years (2011-2013).

Goal/Conclusion

The goal is to understand the participants in the context of their social world and to analyze how pupils with Fragile X Syndrome manage their daily lives at school. This is not based on assumptions about how education should be, but rather how it actually is.

- Identification and analysis of situations, mutual understanding and misunderstanding
- Transitions, rituals, interactions, structure of daily routines, pedagogical situations,
- Which questions do teachers have to ask themselves when working with students with FXS to enable the most successful, effective learning?

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Excerpts from fieldnotes

“The red dot”

„His teacher is standing at the other pupils’ desks, leaning forward towards them and talking quietly. Simon calls to her, but so quietly and softly spoken that she does not react. „Mrs. Hanke, Mrs. Hanke“. Maybe she doesn’t even hear him. His voice turns whiny and he starts ripping his laminated photo off the folder in front of him. He bites it with his teeth in order to tear it apart, but without success, then takes the photo in his mouth and chews on it. At that point the teacher comes to him and announces with a firm voice that he will get a red dot in his token system.“ (Fieldnotes S2.2)

What is happening here?

- *Simon’s practice seems to be an automatic response. He is not asking how to gain attention, he just demands it. His behavior could be the result of frustration when other actions are not noticed anymore.*
- *The teacher on the other hand interprets this as deliberate provocation and responds to it negatively. Thus his inability to communicate leads to a misunderstanding.*

„The Rocket“

„Today Simon is talking constantly about „the rocket“. He is asking again and again if they will play this game today. Sitting on a bench in the schoolyard he asks me stereotypically ‘Are we going to play the rocket? Today we are going to play the rocket!’ While speaking he fidgets with his hands in front of his face. I am not able to initiate a conversation about this game. He is avoiding constantly my questions if he likes the game or if he is looking forward to playing it. Instead he repeats his sentences or variations like ‘Mrs. Hanke (*his teacher*) is doing the rocket, we are playing the rocket’.” (Fieldnotes S4.1)

What is happening here?

- *„The rocket“ is a game which requires close physical contact. The players are standing very close in a circle holding their hands. There is no distance to a neighbor which could trigger sensory aversion in individuals with FXS.*
- *Simon knows that the rocket is being played at the end of the school day after talking about the behavior management plan. Is this challenging for him, because it could be a negative feedback?*
- *Sometimes the rocket is not played without any prior notice. So his repeated questioning if it is being played today might be legitimate. Unpredictable changes in the routine are very challenging for him.*

„On the basis of these reports and existing literature, we hypothesize that decreases in predictability are aversive to children with PWS and FraX“ (Woodcock et al. 2009, 265). This hypothesis seems reflected in Simons behavior. The occurrence of this game depends on variables he cannot foresee or which cannot be influenced by him.

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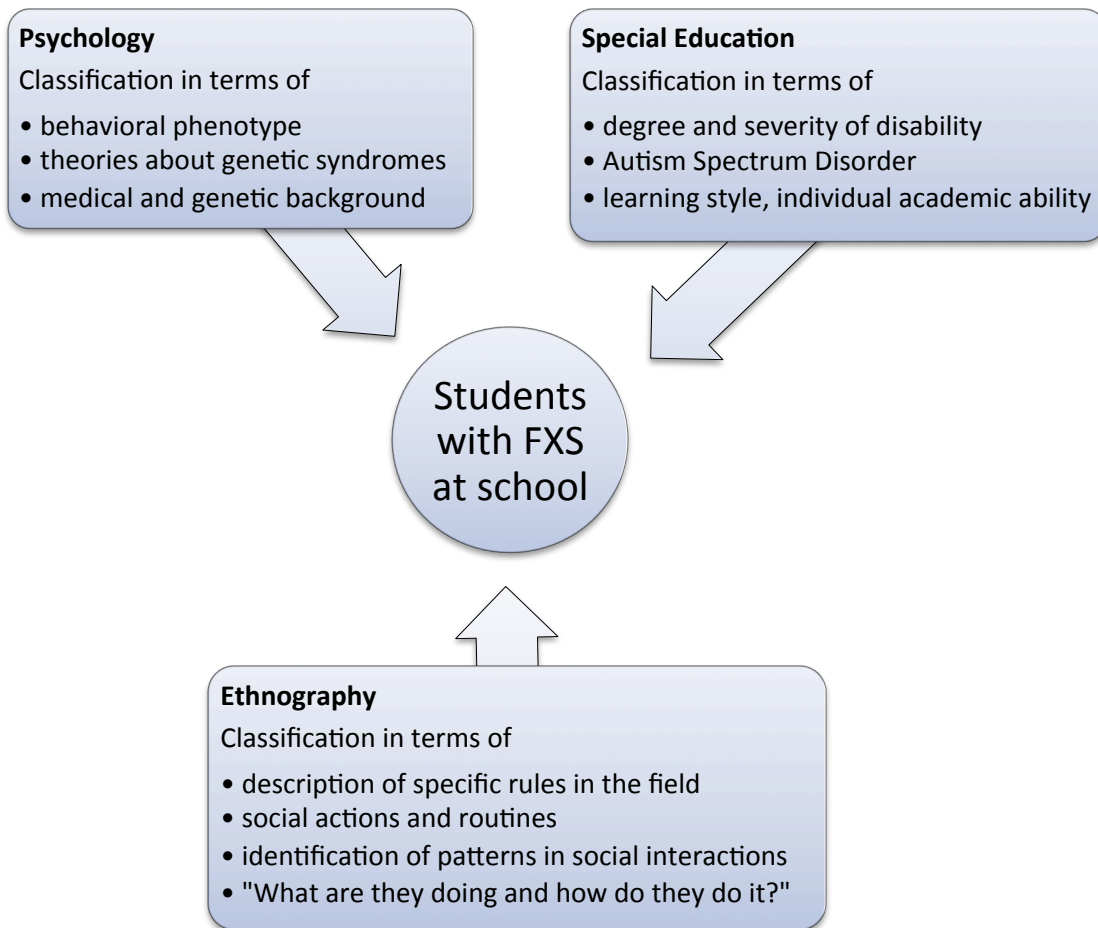


Figure 1: Different approaches to research of genetic syndromes

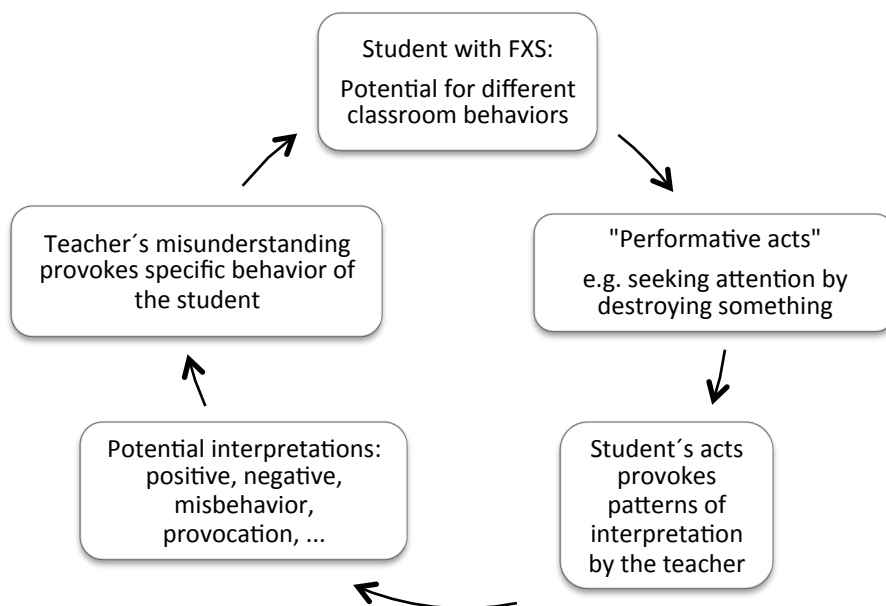


Figure 2: "cycle of misunderstanding"

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Fragile-X-Syndrome

- The most common identifiable cause of inherited intellectual disability and developmental delay,
- Prevalence estimates: 1:3600-4000 in males and 1:4000-6000 in females (Hagerman, R. et al. 2009),
- Behavioral characteristics in males with full mutation may include (Bailey et al. 2008):
 - Developmental delay (96%)
 - Attention problems (84%)
 - Anxiety (70%)
 - Hyperactivity (66%)
 - Autism Spectrum Disorder (46%)
 - Specific learning profile

Literature

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Acknowledgments

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Biography

Carsten Goebell is working as a special education teacher in Berlin, Germany and has multiple teaching experience with students with Fragile X Syndrome and Autism. He is also teaching part time at the Special Education department at the Humboldt University Berlin, where he momentarily is a doctoral candidate on educational and behavioral issues of students with Fragile X Syndrome. He has presented at fragile X conferences of the German Fragile X Association (Interessengemeinschaft Fragiles-X) and on various workshops for special education teachers regarding intellectual and developmental disabilities.

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