

Title	病気の表現活動のエスノグラフィ 「生きづらさ」の つながりと生存の知
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論文の内容の要旨

The purpose of this study is to clarify what knowledge is used to form ties among people who have mental illness or other conditions that make it difficult to live through performance activities. In this study, “ties” include internal relationships among group members, identity formation, and relationships with society. Knowledge is regarded as techniques and beliefs.

Previous studies show that people with mental illness or disorders form ties within groups through empathy generated from commonality. In addition, they form ties with themselves by establishing their identities by changing the value of their illness or disability, and they form ties with society by either opposition or, conversely, assimilating to the majority. However, some studies state that it is difficult for people with disabilities to form ties with other disabled people because of the diversity of their experiences. There is also the risk that some could feel self-blame if they can't change the value of their traits. In addition, if they claim their own identity, it could be assumed that their problem is only “their” problem, and that they are not concerned about other people. As such, clarification on how to form ties beyond their own commodity, changing values, and either opposition to or assimilation with society is required.

This study focuses on the ethnography of performance activity as experienced by people with mental illness or other difficulties through their poems, music, and other art forms. Ethnography is a research method based on long-term fieldwork. It requires description of the detail of a person's life and their ways of thinking, analyzed by a person in a specific research field from holistic viewpoint and referring to previous theories. It is said that “vulnerability” plays an important role in the experiential knowledge of people with mental

illness or disability. As such, this study analyzes knowledge from the theoretical viewpoint of vulnerability.

Although performance activity is multi-faceted, in general it refers to ties based on the term *Ikizurasa* (“difficulty of living”), and becomes a place where people actively express their vulnerability or weakness. In addition, it is done beyond the context of social welfare, comedy, or subculture.

The first research finding is that people with difficulty of living form ties with each other by crossing plural contexts such as social welfare or subculture in addition to empathy by commodity, and by using differences as resources. The second finding is that they regard themselves as weak or vulnerable rather than changing the values of their traits. And this way of thinking become knowledge of them. The third finding is that they form ties with society by including many types of people having difficulty of living within their community, and by practicing as a subculture. The last finding is that they form ties by expressing their “survivorship.” Though it is said that vulnerability is important to consider in the knowledge of people with mental illness or disorder, “survivorship” exists on the back of vulnerability, and survivorship connects vulnerability and strength in the form of a practice, such as vivid performance. Previous studies show the importance of vulnerability in the formation of ties by people with mental illness or disorders. This study shows vulnerability or weakness is a representation of survivorship. Vulnerability is spread beneath the knowledge of people with difficulty of living.

This study reveals the knowledge of people having difficulty of living, based on survivorship. Vulnerability is strongly related to survivorship, and it is considered that this finding is true not only for people with difficulty of living in terms of performance activity, but for the general population suffering from mental illness or disability.

Key words: Difficulty of Living, Performance Activity, Knowledge, Vulnerability, Ties, Survivorship

論文審査の結果の要旨

本論文は、病気や障害、生きづらさを抱える当事者たちの諸問題（孤立、自己否定、偏見等）を踏まえながら、それらの経験知を有する当事者が、どのように当事者間および社会との関係を構築し、自己規定しながら「つながり」を作っていくのかを明らかにすることを目的としている。

新潟市を活動拠点とし、東京その他でも活動を展開する、生きづらさを抱える当事者たちによる表現活動を主たる対象としたエスノグラフィという形を取る。具体的には、杉本が数年にわたってボランティアをしながら関わりあいをもちつつ調査を実践している「こわれ者の祭典」およ

び「K-BOX」の諸活動が対象である。短期調査を行なったアルコール依存症の自助グループとの比較も考察に活かされている。

本研究の特色のひとつは、(狭義の「疾患」や「障害」ではなく)「生きづらさ」という伸縮・拡張する枠組みで参集し、自らの病気や障害などの生きづらい経験を(笑いや自虐なども含んだ)パフォーマンスという形態で不特定多数に公開するという、事象として非常にユニークな、当事者活動の詳細を描いていることにある。

従来のセルフヘルプグループ研究で扱われてきた、共通性による共感による当事者たちのつながりのみならず、当事者間の差異を差異のまま活用すること、「福祉」と「サブカルチャー」という文脈を行ったり来たりする(文脈を越境しながらの)活動であること、病気や障害を「弱さ」を基盤として自己規定の1つのあり方を示していること、(先述した)伸縮・拡張する枠組み(「誰でも当事者になりうる」という枠組み)による活動であること等々、種々の興味深い論点が詰まっている。

本研究の意義として、従来論じられてきた、当事者が抱える限界を克服する可能性を有する事象を分厚く描いたことにある。提示された事例には、共通性での参集が生み出す排外的な状況から生じる孤立を緩和し、価値転換の容易でない人々に自尊心を付与し、当事者の権威化を回避し、狭義の当事者性に封じ込められてしまう状況を回避する体験的知識が詰まっている。障害者問題、種々のメンタルヘルス問題などに関する保健福祉施策における理念・方向性の拡張にも寄与しうるものを提示していると考ええる。

エスノグラフィの記述に拙さを残し、「知識」「生存」などの概念規定や分析の構図に詰め残すものの、学術的・社会的に意義を持ち、貢献するところが大きいと判断する。よって博士(知識科学)の学位論文として価値あるものと認めた。