

Original Article

A Caring Science Study on Suffering in Outsidership

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Abstract

Background: Fellowship with other people is fundamental for every person's life, health and wellbeing. Despite this many experience outsidership in our society today.

Objective: The aim of this study is to present what outsidership means for the human being and what suffering a person may experience in outsidership.

Material and methodology: Outsidership is studied through narratives from foreign students, as well as from persons who have experienced outsidership in relation to a religious community. The main methodology used is hermeneutics and therefore the material was analysed through content analysis and hermeneutical interpretation.

Results: The result indicates that outsidership can lead to social pain, collective rejection, stigma, shame, suffering related to care and mental illness. Outsidership that is by own choice, temporary and where the person's social network and foundation in life remains, can lead to that the person learns new social codes and is able to create a new sense of belonging. On the other hand outsidership experienced in relation to a community, with strict rules and boundaries, can lead to a suffering that is much deeper and hard to endure. Being excluded from a fellowship and not feeling welcome might lead to mental illness.

Discussion: An involuntary outsidership often leads to deep human suffering and requires care and understanding from nursing staff. The study shows that health professionals do not always know how to encounter patients suffering from outsidership. Thereby there is a need for more knowledge and understanding about outsidership in healthcare.

Keywords: outsidership, suffering, hermeneutics, content analysis, caring science

Introduction

Fellowship with other people is fundamental in every person's life. For many people fellowship, or a sense of community with others, is a source of strength and important for health and wellbeing. On the other hand can a lack of fellowship lead to loneliness and outsidership which affects a person's health negatively. According to Hyypä (2007) fellowship, or social capital, is very important for a person's health and wellbeing. Self-esteem and a sense of security are strengthened when one can identify oneself with a group. Belonging to a group can also have negative consequences, if the group

sets strict boundaries between those who are allowed to belong to the group and those who are not allowed to belong. In this case the fellowship can then feel more like a prison than a safe place. Strict boundaries may create fear of exceeding these boundaries, fear of ending up on the outside, becoming alone and isolated.

Outsidership is a phenomenon that is discussed more and more in our society today, in different contexts and situations. Outsidership as a phenomenon is experienced for instance by people with long-term mental illnesses, unemployed young people, children and adolescents with physical disabilities as well as

people with refugee- or immigrant background (Erdner, Magnusson, Nyström & Lützen 2005; Fägerskiöld & Mattsson 2010; Hammer 2000). Outsidership has been studied from different scientific perspectives and many different concepts are used to describe the phenomenon. Within sociology and pedagogy science the concept social marginalization is often used. Schjellerup Nielsen (2006) discusses how children and adolescents become marginalized because of e.g. their social status, popularity, school success or cultural background. Social marginalization means that someone is alienated, stigmatized, devalued or excluded from a sense of belonging and fellowship. Williams (2001) in turn uses the concept ostracism in his research, which means being ignored and excluded by one or more others. Exclusion and alienation can be done for instance by giving others the "silent treatment". MacDonald and Leary (2005) use the concept social pain which is defined by an emotional reaction to the perception that one is being excluded from or devalued by desired relationships or groups. Nilsson, Nåden och Lindström (2008) use the expression "outsider's loneliness" to describe feelings of loneliness and isolation that are a result of the loss of fellowship.

Outsidership is often characterized by losses. Losses can be e.g. changes in body image, a limited social life, friend- and family relationship problems as well as unemployment (Klaesson, Sandö & Berterö 2011; Peace 2001; Hill 2006). Studies by Erdner et al. (2005) and Nilsson et al. (2008) show that outsidership often has consequences for a person's mental health. It is common that people experiencing outsidership have feelings of hopelessness, apathy or emotional numbness and the risks of depression, anxiety and alcohol and drug abuse are increased. People suffering from outsidership may also experience that they are stigmatized, i.e. feel that they are different and not accepted socially. The feeling of stigma is often connected with shame. People who feel like outsiders feel shame about being different and shame over their situation. (Hammer 2000; Hill 2006, MacDonald & Leary 2005)

Even though we know that fellowship is fundamental for the human being, outsidership exists within different contexts in our society today. Research shows that outsidership affects a person's health and the experiences of being an

outsider and stigmatized may lead to mental illness. Therefore we believe that it is important to study outsidership also from a caring science and suffering perspective. Through a greater understanding of the suffering that a person experiences in outsidership, we wish to give nursing staff a greater preparedness to encounter and care for people that are experiencing illness or suffering due to their outsidership.

Objective and theoretical background

The objective of this study is to deepen the understanding of outsidership and the effects of outsidership on a person's health and suffering. This study has a caring science, humanistic and hermeneutical perspective and knowledge approach. The basic conception of the study is that fellowship is fundamental for all human life and that the human being seeks fellowship where she can give and receive love, and be aware that her existence here and now has a meaning. (Lindström, Lindholm & Zetterlund 2014). If a person does not feel welcome in a fellowship, she might lose hope and joy in life. According to Eriksson (2006) suffering means a violation of a person's dignity. To be able to encounter and give good care to those suffering from outsidership, we must first gain understanding of what suffering this person may be enduring. Then we can better care for and alleviate the suffering that outsidership means for this patient.

Material and Methodology

The data material was collected from informants from two different groups of people, who both were considered having experiences of outsidership. The first group consisted of foreign students that are studying in a nursing programme far from their own home country. The other group consisted of persons who had experienced outsidership in relation to a religious community. Through an open inquiry three foreign students expressed their interest in participating as informants. A request was put on the internet page of a support group for the victims of religions. This request led to three people contacting the researcher and wishing to participate in the study. Outsidership in relation to a religious community was experienced both by persons who had chosen to leave the community, as well as those who had been excluded from the community. The data material was collected in form of narratives. The foreign students shared their stories during individual

research discussions, which were recorded and transcribed, while the persons that had experienced outsidership in relation to a religious community shared their stories in written form. The total data material consisted of 57 pages written text.

The material was analysed through a qualitative content analysis according to Graneheim & Lundman (2004). This qualitative content analysis focuses on understanding and interpretation of texts. The texts were analysed with an inductive approach, i.e. beginning with text contents and being open to what the material had to say. The content analysis proceeded step by step, from unit of analysis, meaning units and condensation to sub-themes and lastly themes which gave answers to the research questions. First the whole text was read through several times to obtain a sense of the whole. The text was first divided into units of analysis and then meaning units which were relevant in relation to the research questions. These meaning units were then condensed so that similar meaning units were brought together and abstracted to sub-themes. The central content in the text finally formulated themes about outsidership and suffering in outsidership. The process of analysis and interpretation involves a back and forth movement between the whole and parts of the text, in order to gain new understanding. The results are presented through these themes, which are confirmed by quotes.

Ethical considerations

Ethical aspects become especially important when vulnerable persons participate as informants. Therefore it has been, from an ethical perspective, very important through the entire research process to be aware of and attentive to the fact that outsidership may be a sensitive and difficult subject which may bring memories and unprocessed emotions to the surface. Therefore contacts were created in a tactful and dignified manner. Special attention was paid to protecting the informants and the religious communities' integrity and anonymity. It was important to not harm the informants or cause unnecessary suffering. This was guaranteed for instance by carefully informing the informants about the purpose and the procedure of the study, as well as about their participation, which was voluntary and could be interrupted at any time. The research has been done in a scientific manner

according to the responsible conduct of research, published by The Finnish Advisory Board on Research (2012). An ethical application was done to gain approval for contacting informants and all material and results were presented in an objective and scientifically correct manner.

Results

The results are presented by showing themes that emerged. First themes from the narratives by foreign students are presented, and then themes that emerged from the narratives about outsidership in relation to a religious community. The trustworthiness of the themes is confirmed by quotes.

Outsidership among foreign students

The five themes that emerged from the foreign students' experiences were:

1. Outsidership as social pain,
2. Outsidership as new social codes,
3. Outsidership as a language barrier,
4. Outsidership as an adventure and
5. Outsidership as a sense of belonging.

Outsidership as social pain

Social pain is described as a feeling of being on the outside, excluded and having a limited social life. Social pain is about not feeling as being part of the majority, the majority population, and not feeling fellowship with them. Included in social pain is also the feeling of not being confirmed.

A lack of confirmation may be that you are not taken seriously.

Outsidership as new social codes

Outsidership has to do with social and cultural codes. Outsidership can be a result of that you are not familiar with the social codes that belong to a certain group, and they are different from the one that you grew up with and learned in your home country. In order to feel fellowship, it takes long time to learn new social codes and how to behave within the new culture or group.

It's taken many years to come into the system, just trying to understand things, and still I don't, I'm still learning.

Outsidership as a language barrier

Feelings of outsidership are due, in the beginning, largely to the language barriers that exist. You are not included, due to language

issues, you may be ignored, and it is difficult to become part of the group. With time when you learn the language, this form of outsidership decreases. The feeling of being an outsider also depends a lot on one's own attitude and sometimes the experience might not be negative at all.

They talk to each other but they shut me out in some way.

When you don't know a language very well, you're kind of ignored... and someone can act like you're totally dumb.

Outsidership as an adventure

Outsidership because of coming from a different cultural background may involve even positive aspects. Positive aspects include feelings of being someone special and interesting when you are different than others. Outsidership may mean advantages, like being excused for your behaviour and your traditions. The experience of outsidership leads to that you grow as a person and become stronger. It might lead to feelings of belonging and community in totally new contexts, eg. that you feel a sense of belonging and community with others who are feeling outsidership.

Generally (feeling like an outsider) is a good experience, because it is always good to take and adventure and it's always good to try, but my experience the good part of it, it has strengthened me, in everything, to try.

It's like my life is more interesting if I'm an outsider...

Outsidership as a sense of belonging

Outsidership may also lead to new feelings of belonging and open up fellowship in totally new contexts, eg. that you feel a sense of belonging and fellowship with others who have come from a foreign country. A feeling of fellowship and belonging with others who are feeling outsidership.

We are all foreigners in our class, so I feel like we all are part, we are all in the same situation.

Outsidership in relation to a religious community

Outsidership in relation to a religious community was experienced both by persons who had

chosen to leave the community, and those who had been excluded from a community. The five themes that emerged were:

1. Outsidership as a division between us and them,
2. Outsidership as collective rejection,
3. Outsidership as stigma and shame,
4. Outsidership as mental health problems and
5. Outsidership and suffering related to care.

Outsidership as a division between us and them

Outsidership is described as the division or setting of boundaries between "us and them", between those who are on the inside and those on the outside. The differences between people can be marked by an own language, own culture, the distinction between what is good and bad or about what is the only right way. What the boundaries are made up of can be difficult to see from the outside, because they are affected by many different elements.

The community labels everyone else – the evil world is outside the community and this congregation is the only right one...

Seemingly we are the only group where there are no outsiders, the outsiders are somewhere outside of this community.

The inner language separates us from the rest of the world – a culture that is so different forms a gap between the world and the congregation.

Outsidership as collective rejection

If the religious community maintains a strict inner discipline, an individual might be left outside and collectively rejected if he/she is not able to adhere to the given norms and codes. Isolation, sanctions and conditional love are effective ways to create outsidership. At the same time fellowship within the community can produce a feeling of outsidership in regards to the surrounding society, the "world outside".

There is a strict inner discipline within the congregation. By means of collective rejection essentially anyone can become excluded or shown that their place is on the outside.

On the other hand I felt like an outsider also in the society around me.

Outsidership as stigma and shame

Outsidership can create feelings of being stigmatized, in other words that feelings of guilt and shame are put on you by others. The individual then feels like a failure, weak and inferior to others. It is described as a process where the individual is declared guilty and the community disclaims their responsibility.

I felt endlessly inadequate and inferior to others....

I felt like a failure, guilty and always looking for faults in myself.

Social isolation and sanctions are effective ways of showing a person that he/she is subject to conditional love

If a person can be pushed to the point where she doesn't wish to live anymore, the congregation disclaims their responsibility, she is labelled as weak, a failure and guilty.

Outsidership and mental health problems

Outsidership in relation to a religious community was shown to leave deep scars in a person and have serious consequences for both physical as well as mental health. Mental health problems were for instance symptoms of panic disorder, burnout, severe mood swings, hyperactivity and psycho-somatic symptoms such as sleeplessness, loss of appetite and heart problems. Outsidership can in worst cases lead to serious depression, self-destruction and suicidal thoughts. Even prioritizing your own health before the rules of the group, can lead to exclusion from the group, which has serious consequences for your mental health.

The whole battle left deep scars in me that I still haven't recovered from.

I put my health before the community's rules, and this led to total exclusion from the congregation.

Individuals, who had been able to get through the agony of outsidership, often found a turning point in life and strength to go on. This happened when they understood that it is normal to show symptoms of suffering, after ending up in outsidership.

If you accept that you are a human being and it is healthy to show symptoms, it is easier to

understand the relationship between cause and effect.

Outsidership and suffering related to care

When the pain of outsidership has led to that a person's mental health has begun to waver, many have sought help, protection and support from different social and health care services. Instead of receiving understanding and care, many experienced that they did not receive the help they would have needed or their problems were not taken seriously. The feeling of not being taken seriously and the lack of understanding and knowledge has therefore led to an ever greater suffering. Health care is described as complicated and for some it has been a battle to get care and help at all.

They (health care staff) said: Well you have nothing, you can go back home. I felt that they didn't want to help me.

The lack of knowledge (about religious communities) within health care has made getting help more slow and complicated

Not until after a long battle did I get such care where I became ok with my own feelings.

Quality and trustworthiness

In order to guarantee trustworthiness and quality of the study, the findings have been presented based on the research questions. The results are presented both in text which shows the interpretation, as well as with chosen quotes that show the reliability of the interpretation. Ethical considerations have been important during the entire implementation of this study, such as paying special attention to protecting the integrity and anonymity of the research persons. The material was read through several times to obtain a sense of the whole, and the meaning units were chosen carefully to be able to retain the nuances of the text. There has been a desire to maintain the original text throughout the presentation of the results. Results have been described in an honest and objective manner, according to scientific guidelines, without shying away from the suffering that outsidership may entail. One challenge has been limiting the amount of quotes, without losing reliability. The study is empirically grounded and has external value, since the results are significant and can be used in clinical practice.

Discussion

One of the informants describes: “*You are not part of the people and everybody needs to feel that they are part of something. That’s really important for a person, that they belong*”.

This summarizes the study’s basic theoretical conception, that all human beings long for and need to feel that they belong to and are part of a fellowship. Still there are more and more people, in our society today, who experience outsidership, marginalization and exclusion. Outsidership affects a person’s health and wellbeing and therefore we agree with Smith (2013) that there is a need for more knowledge and understanding about outsidership. In looking for connections between outsidership and the suffering that outsidership might mean for the individual, we can better encounter and provide better nursing care for the patient who is suffering. According to Eriksson (2006) we need to have the courage to meet people in the midst of their suffering and try to understand what is causing their suffering, in order to genuinely meet a person, confirm her suffering and participate in alleviating her suffering.

The results show that there are great differences between how people experience outsidership. Outsidership that is by own choice and temporary often means short-term difficulties and that the person has to learn new things, such as new cultural codes and new languages. If the individual’s social networks and foundation in life remain, he/she can overcome even experiences of outsidership in certain situations. Short-term outsidership can even have positive effects, like feelings of being on an adventure, finding new forms of fellowship and growing as a person. On the other hand the results show that suffering experienced in relation to a community with strictly set boundaries, often is much deeper and harder to endure. Outsidership in this context might mean that a person loses their basic social security. To be excluded and not feel welcome is hard to endure and might lead to that the foundations of life, health and wellbeing are thoroughly shaken. This kind of outsidership evokes feelings of stigma, guilt and shame, which partly are put on by other people (compare Hammer 2000; Hill 2006; MacDonald & Leary 2005). To leave or be forced to leave a fellowship, where you have lived within strict boundaries for a long time, might also mean that

you feel outsidership in relation to society on the outside. Informants tell about a suffering that can even be life-long, including mental health problems and self-destructivity. The individual is forced to take a stand concerning the life he/she lived within the community and the life he/she has now chosen to live, with all the consequences this might bring about. In such outsidership a person needs someone who will confirm his/her suffering and provide assurance that it is normal to show symptoms of illness. The study shows that the suffering in outsidership greatly depends on whether the outsidership is by own choice or involuntary, and if the boundaries are set by the person themselves or by someone else. If outsidership is by own choice and voluntary it is easier to endure, where an involuntary outsidership often leads to losses and deep human suffering. This suffering requires care and understanding from nursing staff. A lack of understanding leads to that these individuals also experience suffering related to care. This study shows that further research is important, especially pertaining to context specific healthcare care of patients with illness and suffering.

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