

Patient Education in Everyday Life - preliminary findings about learning across action contexts

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Abstract

The paper is a part of the ongoing PhD project 'Patient education in everyday life'. The aim is to understand patient education as a case. The study is carried out in Denmark in an outpatient clinic where people are treated after they have been hospitalized with depression in a psychiatric ward. A part of the treatment is to participate in a patient education course. It is supposed to help participants take their disease into account in managing their daily living outside the hospital. The aim is to prevent relapse and recurrence of depression.

The education system in general is based on the assumption that what is learned through education can and should be applied in other situations, for example in work-life or in everyday life. Dreier (2008) points out that people who are participating in family therapy live the majority of their lives in other contexts than the context of therapy. It is in these other contexts therapy is supposed to be useful; just as patient education.

In one part of the case study I explore connections and disconnections between the patient education course and other contexts of action the participants in patient education are a part of. Focus is learning, understood as changes abilities and understanding for participation in a changing social practice.

The theoretical framework is critical psychology, mainly inspired by Dreier's theory of persons in social practice. The methods used for data generation are observations of the patient education courses, texts from the courses, photo-interviews and follow-up interviews with participants in patient education. Furthermore there will be interviews with the professionals at the outpatient clinic.

In the presentation I will show how changes in conduct of everyday life may cause conflicts and doubleness related to coming to understanding with one self, others and us.

Background

My PhD project is named 'Patient Education in Everyday Life'. It is an on-going case study (Stake 1995; Stake 2006; Stake 2010) of patient education carried out in an outpatient clinic in Denmark, where adults are treated after they have been hospitalized with depression in a psychiatric ward. As part of the treatment in the outpatient clinic, individuals participate in a patient education course.

Patient education is designed to optimize self-care and build up competence in relation to

disease-management amongst adults with diseases that require ongoing treatment. Its rationale is to reduce the resources used in the health-care system, while enhancing the well-being and quality of life for the individual (Jørgensen 2005). The health-care system is considered responsible for providing the patient with the knowledge and skills to practice self-care, and the patients are expected to be active, competent and responsible for their own health-care (NBH 2011). Depression is, measured in the

number of healthy life years, the most burdensome disease in Denmark (Kjøller 2007) and has the highest score of “healthy life” lost to the disease in Europe. 70% of patients who are hospitalized in a psychiatric ward due to a depression will develop recurrent episodes, and 60% will suffer more than two recurrent episodes. It seems that the severity and the frequency of depression are increased with the number of episodes (Kessing 2007).

One of the aims of my research is to understand the interplay between participation in a patient education course and conduct of everyday life in other contexts of actions. In this paper I will present some preliminary findings from my investigation of learning across contexts.

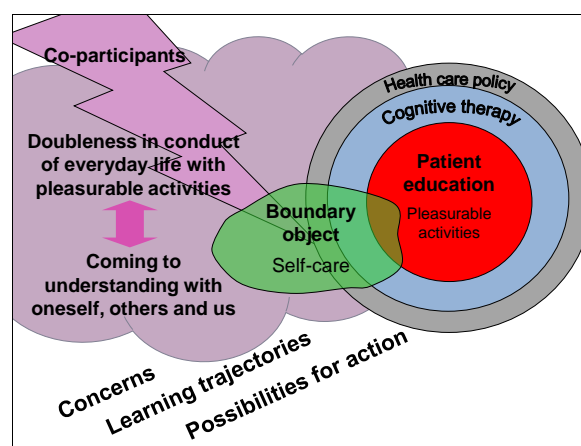
Methods

I analyse the research participants’ conduct of everyday life based on photo-interviews and follow-up interviews in the home of the research participants. The analyses are governed by analytical categories from Danish-German critical psychology such as concerns, contexts of action, self-understanding, learning trajectories and reasons for action. In the analyses the first person perspective is understood in combination with the structures of social practice the research participants are located and take part in. In this paper I explore how learning across contexts of action can be understood. Learning refers to a person’s modification of their abilities and understandings of participation in social practice. Learning is closely related to the conduct of everyday life and to the persons concerns. Learning is understood as open-ended, and therefore the personal learning trajectory is important to understand learning across social contexts (Dreier 2003; Dreier 2008; Dreier 2011). In the analysis of learning across contexts I am inspired by Ole Dreiers Theory about persons in structures of social practice and his notions about personal learning trajectories across contexts of

actions (Dreier 2003; Dreier 2008), by the analytical tool couplings and de-couplings developed by Lene Tanggaard (Tanggaard 2004; Tanggaard 2004) and the discussions of boundary communities of practice by Line Lerche Mørck (Mørck 2006) and self-care understood as a boundary object developed by Lone Grøn (Grøn 2011; Grøn 2012). The processes of analysis are like working on a patchwork, which is an iterative dialectic process between the research questions and the empirical patches. The researcher search for patterns that can create understanding for the case, especially a search of issues. Issues are problematic themes with doubleness and conflicts (Stake 2010).

Findings

The preliminary findings I have tried to illustrate in the following figure are related to doubleness in conduct of everyday life with pleasurable activities, which seem related to coming to understanding with oneself, others and us. In the following I will explain the illustration, but ask the reader to keep in mind that this is preliminary findings.



The red circle illustrates the patient education course. It is primarily two nurses who teach in the investigated group-based patient education course. The course is made up of six one hour sessions during a period of three weeks. In the investigated patient education course the

participants are encouraged to carry out activities they connect with pleasure as a part of self-care. It is emphasized that each individual has to find out what pleasure is, it depends on personal taste.

It is not particular for this course to focus on activities with pleasure. The blue circle illustrates that it is part of a cognitive therapy approach. The loss of pleasure in normally enjoyable activities is one of the main symptoms in depression. In cognitive therapy it is treated by encouraging persons to schedule their everyday life with activities they like.

The gray circle shows that patient education is a part of the Danish health care policy. Patient education is expected to reduce the resources used in the health-care system, and to enhance the well-being and quality of life for the individual.

I found that the research participants conduct their life oriented toward taking care of themselves pursuing the concern to avoid new episodes of depression. To conduct life with activities with pleasure is one of the ways research participants try to take care of themselves. I have used Grøns analyses of self-care as a boundary object to understand this process of learning – the green object in the illustration. Grøn has worked with self-care in relation to patient education for adults suffering from somatic diseases. A boundary object is flexible enough to be adapted in relation to the contexts and at the same time solid enough to maintain an identity across contexts.

I have tried to illustrate that self-care might be seen as a concept in the patient education, in the cognitive therapy and in the health care policy. But self-care is also a concept in the conduct of everyday life seen from a first person perspective. Even though it is adapted and understood differently, self-care can be a link

between participation in patient education and participation in other contexts of action.

The personal learning trajectory is important for understanding what a person perceives as pleasure. For example Georg, who is 61 years old and lives with his spouse. He compares himself with his mother. Recently he read some letters his mother wrote when she was young, and this made him think about her condition and way to function and what makes her happy. He concludes that he is just like her. As for her, it is a pleasure for him, to be social and see lots of people and also to buy new things such as clothes. He has become very aware about carrying out what he likes to do as a part of self-care.

To conduct everyday life is a negotiation with persons around us – the co-participants (see illustration). For George it creates some conflicts between him and his spouse when he changes his conduct of everyday life and starts to buy more things and go out more, because they understand conduct of everyday life in different ways and because it leaves less time for them together.

I found that the conduct of activities with pleasure in everyday life creates doubleness there is related to coming to understanding with one self, others and us. Coming to understanding with one self, others and us is in critical psychology closely related to conduct of everyday life. It involves the person's reasons to conduct his life in a particular way and this involves the persons concerns, dilemmas, conflicts, possibilities and challenges. For example Elise, she is in her thirties. She lives with her husband and their two small children: It is a real break for Elise to read weekly magazines, which she terms 'the worst goop'. Every day she struggles to allow herself to take breaks, she says:

"There are many things during the day I have to give myself permission to do. I have to make

peace with the things I desire to do. I also have to make peace with not wanting to do very much. It is linked to watching television and reading goop magazines [...] I have to accept the idea that I don't have to accomplish big things. It is one of my major obstacles, I have to be useful to make sense of life [...] I talked to the nurse about the fact that I am not feeling better if I carry out activities with pleasure two days in a row. If I do so, I do not feel I am any use and that doesn't make sense for me. I find it hard to accept that I cannot be more useful. My husband will be away a few days next week and it puts things in perspective. It makes me very aware that I cannot take on a huge responsibility. It is hard to accept" (my translation).

It is doubleness for Elise that she, when she was at the hospital, experienced it as an activity with pleasure to read magazines. But at the same time she loses meaning of life, if she is not doing useful tasks. The patient education course, she says, has helped her to work on her own accept of her need to take a break. But still she struggles daily with coming to an understanding with herself as somebody who desires to read gossip magazines as a necessary recreation. Elise's on-going work on coming to understanding with herself involves the specific arrangements in the family. She says she has to put herself and her own needs in the foreground to be able to take care of herself.

Another doubleness is when activities with pleasure become something the person ought to do, which also is related to self-understanding. This doubleness can relate to the loss of feeling anything as pleasure, which is a core symptom in depression. For example Darleen, who is in the early thirties and lives with her husband. When I talk to her about the advice from the patient education course about doing activities with pleasure, she rolls her eyes, and tells me, she does not feel any pleasure at all. She is doing what she used to feel desire for in the past. When she for example stays half an hour in bed in the morning, it is because she used to enjoy that.

When she goes to relax in the sun, it is something that used to be a pleasure. But she still carries out those activities. She has made a rational decision to do so. She believes it is good for her and somehow it is also satisfying for her to accomplish activities. Her husband becomes proud when she is active. Earlier he felt, that she spend too much time in the sofa.

Another example is James, who lives with his wife and their two children. At the first interview he is on paternity leave. He tells me:

"... The patient education course made me aware that I have to take time to do activities with pleasure; I have to be aware of that. Earlier I would clean up and make the beds, and only after that would I allow myself to sit down and read a book or watch television. Now I have to say to myself; 'sit down and do something enjoyable', in a demonstrative way. I have tried to do so in my paternity leave [...]. This about, you doesn't necessarily need to take care of duties before you have a nice time and relax a little. Well - I was raised with eating dark bread before eating white bread" (My translation)

James has to force himself to carry out activities with pleasure and it is completely different from the way he was brought up and sees himself. James does not experience to carry out the activities with pleasure as something that makes him feel better. But he has taken a decision to change his conduct of everyday life based on knowledge from the patient education course. He thinks that his conduct of life is an important part of self-care and treatment, and therefore he does so. But it is doubleness and a struggle when pleasure becomes something he ought to do and is in conflict with his usual routines and self-understanding. The arrangements are also important. Because of the paternity leave James has time to carry out both the activities with pleasure and the duties. It is only a matter of order, he says. Once he begins at work it is no

longer just a matter of order. Then he will have to omit some activities.

Conclusion

To sum up: when the participants in the patient education course change their conduct of everyday life as a part of learning across contexts of action and thus carries out activities with pleasure in their conduct of everyday life, it is a learning process that:

- relates to their concern and orientation toward taking care of themselves and/or their family
- relates to their concern to avoid new episodes of depression and hospitalization
- involves coming to understanding with oneself, others and us, which may create doubleness and conflicts in the conduct of everyday life
- involves their personal learning trajectory and their possibilities for action

It can be a struggle to take care of oneself. Grøn shows in her analyses of self-care as a boundary object that, from the patients' perspective, self-care can be experienced as pleasure, a duty and as bad conscience. In my analyses self-care can be doubleness in itself when activities with pleasure become something you ought to do.

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