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Understanding Professional Care from the Viewpoint of Care Receivers and Care Givers – The Necessity of a Special Care Rationality

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1 Introduction: In search of an empirically based understanding of Care

The paper looks into the question, what helps whom in the realm of social work and nursing, which form of help is needed and how is this need defined by care givers and care receivers. Its goal is to comprehend requirements of a subject oriented approach to care in long lasting professional processes. The analysis of this question is based on a new qualitative research study at the University of Applied Sciences in Frankfurt/ Main, Germany at the department of Health and Social Work. Ways of understanding care by the involved actors – care receivers and care givers - in the fields of psychiatric ill, physically handicapped and dependent elderly people will be looked into in order to grasp the various dimensions of subject oriented care and its preconditions. As a theoretical guideline this empirical approach is based on the assumptions of the concept of a special “care rationality” (Kari Waerness 2000) including the necessity of institutional support and the possibility of self-determined action, both of which are endangered in times of neo-liberal politics with its logic of economical calculations (Gerhard/ Knijn/ Weckwert 2003, Newman et. al. 2008).

2 Care in the context of the gender theoretical international Care Debate

Making care work a public issue about thirty years ago was – and still is – politically important in order to point out the hidden base of welfare states (Brückner 2010). In many countries this fight against injustice was linked to political action with the aim to make (mainly) women’s unpaid or badly paid work in families, in communities and in social, educational and health institutions visible. Nowadays care as low paid work in families or institutions is often done by migrant women, coming from poor Eastern or Southern countries to rich countries in the Northern and Western part of the world (Rerrich 2010; Lutz 2009). The issue of showing the unjust handling of care often is treated in an emotionalized way, since it questions the hegemonial construction of gender relationships and puts men more often than not in a self-defensive position Beckmann 2008). That is why social sciences need to deconstruct the role of care in society: Care on one hand is idealized as devotion and linked to traditional femininity by traditional women and men, on the other hand by the feminist movement rejected as exploitation and linked to dependency (Schmidbaur 2010). But there is still another reason for care being such an emotional topic: care reminds all of us of the human condition of mankind as vulnerable and mortal. That makes care an existential issue, no matter how it is organized and culturally connotated (Nussbaum 2003; Lister et. al. 2007).

In today’s international discussion on care, care is understood as a societal necessity - transcending the public and the private sphere, since it takes place in both spheres (Brückner 2008). Care includes the task oriented component of “taking care of” as well as the emotional component of “caring about” in familial, informal and formal personal services and “taking care of oneself” as a sign of human interdependency (Moser/Pinhard 2010). Caring about others and caring for your self need to be seen as belonging together, thereby pointing out the difference between care and caritas, the Christian idea of selfless help transferred in bourgeois gender ideology mainly to women. At least in parenthesis it needs to be added that neo liberalism propagates another understanding of self care in the sense of self optimising your potential in an economic sense, which is a perversion of the idea of self determination and personal rights (Ludwig 2006; Preglau 2010).

Carol Thomas gives a definition of care, which still seems appropriate in its broadness:

“Care is both the paid and unpaid provision of support involving work activities and feeling states. It is provided mainly, but not exclusively, by women to both able-bodied and dependent adults and children in either the public or domestic spheres, and in a variety of institutional settings” (Thomas 1993: 665).

The advantage of this all embracing definition is to reveal the relationship between private obligations and public services as well as between paid and unpaid services and between non qualified and qualified work - thereby making the normative base of care visible and showing how it is interwoven in the respective societal set up (Theobald 2008). It is therefore necessary to always take the specific contexts of care processes into account in order to respect the specific needs of care givers and care receivers - opposing neo liberal intentions of time limiting schematization and rationalization (Waerness 2000; Tronto 2008). Mary Daly and Jane Lewis (2000) differentiate between three dimensions of care: 1. work, 2. a normative frame of obligations and responsibilities, 3. an activity which causes financial and emotional costs and transcends the private and the public sphere. This makes care a concept capable of analysing welfare states on the macro and the micro level including the so far hidden activities mainly of women as base of social politics and social policies.

3 Defining Care in the context of our research

The aim of our research was to develop a definition of care on the base of care actor’s viewpoints as found in the transcribed texts from our interviews with 40 care receivers and care givers all together. These male and female actors were major participants in 12 private care networks, each formed around a long term care needing man or woman in the work field of psychiatric illness, physical handicaps and old age. All 12 care receivers had an official diagnosis making them eligible for benefits and services from the welfare state. Their living situation was either strongly concentrated on their home or they took part in day care institutions for elderly or for ill persons or in rehabilitation/ reintegration institutions.

For the research we combined different methods following the idea of method triangulation (Flick/ Kardoff/ Steinke 2005): question guided and narrative interviews, questionnaires, network cards and participant observation. The interpretation of the data was done with the method of content analysis formulating categories in several steps of abstraction from the text material (Schmidt 2003). The dimensions used for the analysis of the texts stem as well from the theoretical framework explicated before, since it guided us in formulating research categories as from research material itself. Taking the viewpoints of care receivers and care givers into consideration four central dimensions of care in professional contexts could be shown: the institutional frame, capability of action including relationship building, norms and self care:

- Care frame: the institution itself and the question of the financial basis of livelihood,
- Care actions: performing activities and building relationships,

- Care norms: ideals and orientations for actions,
- Care for oneself: forms of self orientation and self protection.

Since our focus was on professional care, the question of how care is institutionally framed and how the existence is financially secured were the base of the interpretation of our data. At the centre of our attention though, was the dimension of action without which care is not thinkable. These actions are explicitly or implicitly based on ethical and normative convictions of the actors. And finally care stands for the fact of human interdependency and therefore caring for oneself just as caring for others is a condition sine qua non.

4 Research results: Care in the perspective of care actors in institutional contexts

4.1 The frame of professional care processes

Formal care is linked to institutions which either constitute a protected frame or endanger care processes, depending on the degree of adequateness of the respected personal services such as day care, group work, rehabilitation, counselling, personal assistance and care services.

- Caring Institutions and their functions for the care receivers:

Depending on the specific problem and the care needed, the care receivers (7 women, 5 men)[1] use either predominantly group activities (mainly psychiatric ill and old persons) or case work (mainly physically handicapped persons). Gender specific is the hope in learning to handle technical auxilaries (men) and the use of institutions for finding friends (women) amongst the users.

The psychiatric ill persons find especially day care important, wanting structure for the day, continuity of services, openings and professionals and good cooperation between institutions, since they all have long term experience with various services. The use of the day care is quite individual and shows how important it is to give self-will a possibility:

Mr. Appel (cr, burn-out illness): „The day care gives me very much support. Through this I have a regulated every day life (…). I have a task to do (…) and a stable frame.”

Ms Abel (cr, mania and depression illness): „Because of a loss of friends through a mania I started to build up a new group of friends with the help of the day care."

For disabled actors institutions are important for their individual advancement in independence referring to work or to personal ability.

Ms Achenbach (cr, wheel-chair user since birth): „She [social worker of an employment service for the handicapped] supports me in the sense of looking together with me for suitable jobs. She makes suggestions on where I could apply, where I could do a practical course. (…) I looked myself all the time, but there is more of a support with her, she looks at places, where I would not have thought to apply.”

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[1] All names are fiction: care receivers’ names start with an A, care givers’ names with E and F (if there are two in an individual network); the interviews have been translated by the author.

For elderly actors concerning day care it is most important to feel well under four aspects: having an occupation and being cared for, the quality of the group, the acceptance of the handicaps and the friendliness of the professionals. Here an example:

Ms Arnold (cr, diabetes illness): „I thank God that I am able to come here, I am always happy to go. On these days [three times a week, M. B.] I can get up much easier in the morning. (…) There are always things to do, mental training and … sitting dances. I can't just now list it all, but it does me very well."

- Caring Institutions and their functions for care givers:

For the professionals (12 women, 2 men) of all work-fields it is decisive to have sufficient possibilities of doing their tasks in their own way including decision making. What they see negatively – and negative comments to their work are more prominent in their answers - concerns time lack and too many clients:

Ms Felder (cgp, work-field disability): „I like my work very much, because it covers most different areas. (…) Since I always need to know how someone feels today – that is relevant for my way of teaching mobility to blind persons (…) counselling very clearly belongs to my task, (speaks quietly) even if my boss thinks it doesn't (laughs)."

Ms Everding (cgp, work-field elderly): „I like my job (laughs) (…). Here I get the feeling, that I can take my time when I find it relevant to the helping procedure (compared to the job before where this was not possible, M. B.). A woman of my group fell and had to be treated. (…) To be able to go and visit her since it was important to me, because she was important to me, because I was a significant person for her."

Also for professionals the possibility of self-will is important in order to make a good job and to feel well.

- Caring Institutions and the livelihood situation of care receivers and care givers:

Mainly psychiatric ill care receivers feel insecure about their financial situation, whereas disabled and elderly actors do not mention the topic much, which shows that the welfare state did not manage to give psychiatric ill care receivers a sufficient feeling of material safety.

On the side of the professional care givers only the two men mention earnings explicitly which could be linked to a gender bias in so far, as traditionally earning a lot of money for women in general and especially in helping professions is not a priority.

4.2 The Care Action: Giving support, doing counselling, doing relationship building

Care action including emotional work is at the heart of doing care as a relationship oriented process, which is oriented towards another person or even better is - if possible - to a smaller or bigger extent co-produced by the care giver and the care receiver. Without the action part there is no care and without interpersonal contact care receivers become objects instead of subjects of care.

- The perspective of care receivers:

Most statements of the receiving actors are characterized by a close link between activity and communication that means both the materialized form of help and the relationship to the professional matter and belong together. For psychiatric ill actors this link reaches from the positive effect of material support on the relationship via feeling emotionally supported in face of a support action to being better able to carry one's fate because of sensitive counselling. So Ms. Albrecht not only was glad about the support to receive financial aid, but also because her social worker became "really mad" and phoned the social institution in charge to make sure she got her right.

Ms Albrecht (cr, borderline illness): „With this institution I had problems, she [her social worker Ms Emmel, M.B.] became really mad and said: "You have a right to this financial support". Usually I do the phoning myself, but at that time, when that happened, I was not able to. Then she always called on the phone and said: „This woman needs to eat something, so write her a voucher for 50 €!" She called and I only had to pick it up, which was good for me".

For the disabled actors it is most important to be able to rely on the care givers and to find their aim to be as independent as possible accepted, because handling dependence is a big issue for all of them may be especially for the men, since masculinity is generally identified with independence.

Mr. Adam (cr, wheelchair user since a short time) is satisfied with his daily care, but his aim is to be as independent as possible: „one is glad, not needing help any more".

Mr. Asanger (cr, severely handicapped since birth) is glad about the support he gets but is also very clear on how he wants to have it done in order to feel the master over his life: „I feel especially good, when I can be confident, that they [his assistants, all women, M. B.] do everything the way I would do it when I could. So that I can say: „okay, you know what you have to do, please do it just like I tell you to" and that this will happen."

The elderly actors do not say much about care actions, they rather talk about help in general terms and if they feel good with it or not.

- The perspective of care givers:

Depending on the work field there are different activities and various interpretations of the workload involved but the overall reflection of the necessity of relationship building is similar in all fields. Especially in the work-field psychiatric illness there seems to be a growing need of self defence the higher the degree of action and the lower the degree of counselling as part of their professional tasks.

Ms Ebert (cgp, work field psychiatric illness) comments on how successful the work in her day care centre for patients is, but she is anyway afraid of not finding professional recognition for this. She sings for example with the group of patients and is delighted that after a while two clients dare to present a song because they feel accepted in the group and by her: „Because I have the feeling, that one can support people here successfully by strengthening their self-esteem with very basic offers. But to the outside world these offers are partly seen as petty little matters." This outside-world includes also her employer who stresses the need on actions towards reintegration into the workforce and not so much social group work.

In the work-field of disability most important is relationship building in the context of personal bodily assistance. The work of the professionals becomes much easier and more pleasant when the care receivers cooperate during the process of assistance.

Ms Ehrhard (cgp, work-field disability) highlights the relevance of becoming a team with the care receiver in order to be successful in her placement work: „Since we [her interviewed client and her, M.B.] know each other for quite some time, there exists some closeness. We are a reliable team. Both of us know exactly what one can expect of the other without big words. (…) There is no preset scheme, it's rather that we are in contact with each other, and think it over how we can do it best."

In the work-field of the elderly next to performing necessary activities, it is very important to sense wishes and to know about personal peculiarities in order to be able to respect them.

Ms Everding (cgp, work-field elderly) leads a discussion group for persons with dementia, which needs sufficient insight in the situation of the group members, what she calls "feeling": „My sense is that Mr. Altdorf [her interviewed client, M.B.] feels uneasy when he comes. He would prefer to leave together with his wife who brings him. Then I try to welcome him, accompany him and smooth this transition phase for him. I say for example, "if you like to, you could sit next to Mr. X", then at least he can be sure that there is someone he knows. (…) Those are the little things which I try, that he feels well and can talk about his illness and comes into contact with the others."

4.3 Norms

- Norms in the eyes of care receivers

Care norms are historically and contextually defined in various ways and it is rather new, to explicitly respect the views of care receivers and to regard them as equal citizens. In that sense it is remarkable, that one of the care receivers demands respect and probably not by chance it is not only a man who does so, but also a person in a formerly high social position:

Mr. Altdorf (cr, elderly with dementia): „What I find important is things to keep on going like cultural events and sports (…). But I would … do it only, when somehow in society … it would be made more open [for dement persons, M.B.]. But it isn't. (…) So I can not do it any longer."

But all together the care receivers speak not much about norms in society and normative aspects of the care they need, but interestingly enough they speak about the care they are able to give, that seems to make them a self-respected person and an honourable citizen:

- They talk about helpfulness and give examples of themselves helping others like Ms. Arnold (cr, elderly with depression) who in her day care for the elderly guides another old lady on walks: "Here [in her day care, M.B.] is an elderly lady who can still walk very well, but in her head she is already quite absent minded, with her I go on walks (…). I am nice to her, I practically guide her, she no longer has a sense of orientation, she let's me do everything (…). And she always likes that."

- They stress the reciprocity of interaction and of give and take by telling, how they themselves give to others like Mr. Asanger (cr, disabled): „Because I'm a human being, who not only takes, but who tries to give a lot. "

- Norms in the eyes of professionals

Two normative aspects of care are mentioned by professionals of all three work-fields: Supporting independence and supporting integration/ inclusion as part of their vision of societal justice and participation. On the level of care work this includes equality in the context of an asymmetrical relationship:

Ms Eich (cgp, work-field psychiatric illness): „Being psychiatrically ill does not mean someone stands below me, therefore I want to work on equal height."

Valuing independence can also include the acceptance of self-will to the point of stubbornness even if this is not always easy and sometimes on the edge of self-destruction:

Mr. Fengler (cgp, work-field psychiatric illness): „Ms. Auer [his interviewed client, M. B.] always succeeds to hold on to her self-will, what I can value, because that is the goal. I do not want to counsel her towards dependence, but towards independence, that's why I like it, even when it leads not always in an optimal direction [spending more money than she has, not going to day care but hanging around on the street, when she does not feel well there, taking her former violent husband in etc., M. B.] ."

The possibility of integration is linked to the societal structures which often rather lead to marginalisation.

Ms Eich (cgp, work-field psychiatric illness): „That there would be more acceptance in the outside world, that an institution such as this one [day care, M. B.], would not be so necessary (laughs), but that is a utopian idea. That (…) the clients would be more helped especially by neighbours, friends, that there wouldn't be so much fear, that the clients would not need to safeguard themselves so much ".

4.4 Self-care

The term self-care has itself a moral touch since it is widely understood in the sense of caring for one's own well-being in a positive way (Schnabl 2005). It is far from being clear according to what criteria well-being could be defined, a difficult question that also can not be solved here.

For the few care receivers who say something to this topic, self-care stands for attentiveness for oneself, to open up for the necessity of care in the sense of learning to deal with dependency. All five care receiving men make it a point that they need to learn to accept help, but only one of the seven women mentions this aspect.

For the also only a few care givers mentioning self-care, it mostly stands for prevention of burn-out. This prevention can come very late as Ms Dallmann reports drastically, who works as personal assistant of a very heavily disabled man.

Ms Dallmann (cgp, work-field disability): „Where I said, I need to draw a line it does not make sense any longer like this! For the first time I decided this for myself was when I came home very late at night from work. And we have a dog, which always picks me up at the front door. I enter the house, the dog comes and I trample upon him so that he flies behind the umbrella stand. That was the turning point for me: Finish, end! Now or never! And that's what I did: I took a brake for more than half a year".

Amongst the care givers the two men are the most explicit about self care and they are the only ones mentioning supervision as a helpful form.

Mr. Etzel (cgp, work-field psychiatric illness): „I am good in drawing a line [between himself and his clients, M.B.] (…) But I do have my professional support systems. That includes the contact with colleagues, permanent informative exchange and if I want to my own supervision".

All together it seems that self care as explicit part of caring has not really reached care actors yet.

Implicit forms of self-care are more numerous though: most of the care-receivers have an active approach to the possibilities of social institutions and use them more or less in their own ways and many of the care-givers look for possibilities of developing their own way of handling their tasks like Ms Emmel.

Ms Emmel (cgp, work-field psychiatric illness): „I find it very human, the work here. (…) The patients get a lot of offers, more than is obligatory. (…) I also have liberties, where I know, I can do it that way in my work".

5 Summary

The result of our research can be summoned up as giving proof to the concept of the necessity of a special care rationality (Waerness 2000), since it could be shown how important to care actors are the aspects of process oriented empathy and negotiation in order to strengthen care receivers as persons and to improve their life situation. To achieve these goals sufficient freedom of action as well as a supportive framework are needed for care receivers and care givers alike (Senghaas-Knobloch 2008, Fraser 2003). Frame, action, norms and self-care are dimensions of an understanding of care which is complex enough to grasp various care settings under this concept:

- On the level of frames care needs holding institutions signified by continuity and allowing self-will. Professionals need to be granted sufficient choice for appropriate actions and sufficient degree of decision making as well as sufficient time for care.

- On the level of action context appropriate combinations of activity and relationship building are necessary with time to speak with each other and to interact.

- On the level of norms reciprocity and equality in the context of asymmetrical relationships play an important role, related to issues of recognition and partnership.

- On the level of self-care a main topic is opening up to care processes and limiting care processes as two sides of balancing closeness and distance.

As empirical finding can be formulated: Care is understood as having a reliable and holding frame with chances of forming the supporting process, and enabling a relationship-based realm of activity on the normative base of reciprocal acceptance, - including the protection of the self.

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