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The Emergence and Role of Client Perspectives in and on Cancer Treatment¹

Summary

This paper is divided into two parts: in part one I give some examples from a study of how patient or client perspectives on treatment and life with cancer are "discovered," addressed, included and shaped within cancer research and treatment after World War 2. In this first part I draw on analyses from my Ph.D. thesis about the concept of quality of life and psycho-social research on cancer, in which I focused on the developments and interrelationships between (1) welfare state forms of governance, (2) the practice of cancer treatment and its relation to research, and (3) clients' relations to treatment regimes and a life with cancer. I argue that the client's perspective is represented in medical practice in many different, and often problematic, ways. A core problem is that this perspective is often represented from a third-person point of view, not from a direct first-person point of view. I find a number of reasons for this. The lack of first-person involvement is not isolated to medical practice but is also obvious in the psycho-social practice that evolves in relation to medical treatment and research in the last part of this century. The conflict around this is reflected in psychological theories about illness and disease that are formulated in this period. In the second part of the article I discuss the directions in which psychological theory has to develop in order to contribute to the recognition and involvement of first-person perspectives in medical treatment and research. The aim of this discussion is not limited to understanding life with a specific disease such as cancer, but is, in a broader sense, to understand how we as subjects handle everyday life with biological changes of bodily function.

¹ This article is based on a paper presented at the I.S.C.R.A.T. conference in Århus 1998.

Cancer treatment and research, from an historical point of view, has been dominated by medical doctors, their medicine, medical technology, and medical discourses. But numerous other parties have been involved in the development of this praxis. Contradictions, power-struggles, and different interests at many levels characterizes this field of praxis. Not only is there an obvious contradiction between patient and professional, there is also conflict within the group of medical professionals: Private-practitioners versus hospital doctors and clinicians versus scientists typically embody different conflicting parties. These conflicts are not universal, but change over time and between different places. Patients also do not form a uniform group with common interests, standpoints or perspectives. It is therefore impossible to talk about *the* medical discourse or *the* patient perspective. The field of praxis is characterized by conflicts and often unpredictable dynamics and alliances. A number of themes can be identified around which these struggles of influence and dominance have evolved: The demand that treatment must be based on scientific proofs or: the idealization of natural sciences as a golden standard for good medical praxis. Another important theme has been

the recognition and involvement of the client's perspective (Forchhammer, 1995).

Ways of looking at or recognizing clients' perspectives emerge from particular challenges to existing practices and contradictions among its various involved parties concerning what constitutes good practice. Particular notions about psychosocial dimensions related to cancer treatment and life with cancer unfold and psychological and subjective dimensions are addressed and conceptualized. The construction of a psychosocial discourse of life – and death – with cancer is thus a vital part of the process of recognizing the client.

Welfare state medical technologies in different ways make up a number of new challenges to the recognition and involvement of the patient perspective. On the other hand a focus of interest on clients' perspectives is not a direct effect of technological innovations but is interrelated to changes in welfare state politics and the actual way different parties handle these changes. I will give three examples to illustrate these inter-related processes:

The history of client perspectives on cancer and the fight for acknowledgement of modern medicine

In the archives of the Danish cancer association I found records of written patients' stories. The physician Koch, who was involved in the early attempt to identify, categorize and develop a system of cancer diagnoses, collected and classified the stories. The client's perspective was now handled as data, not as an account from a person but from a representative of a diagnose-group. The client's perspective had to be systematized in order to be meaningful in this praxis.

Koch, the physician, noted where and when patients recognized unusual signs on their bodies, and he was occupied by identifying stories of peculiar events that might have led to the outbreak of cancer: For instance: a man had been bitten by a horse, another exposed to tar, a third cancer victim lived in a swampy area.

Making a diagnostic system is an important starting point for creating the modern clinic (Foucault, 1973, Juul Jensen, 1986). But the disease has to be named, isolated, and described in exact terms. Among many other things this process also involved a recognition and construction of client perspectives. The recognition of client perspectives is in this example on the one hand a tool in the process of making modern medicine acknowledged as a science, but it is also a step in a long process of transforming persons into patients, a process that can only be fulfilled if the person actively takes part by developing skills of bodily self-consciousness, sensitivity to specific signs, and changes of bodily function and self-reflexivity.

Treatment technology and client perspectives

The introduction of chemotherapy right after Second World War is another example of how patients' perspectives were on demand in medical praxis. The first generation of chemotherapy was developed on the basis of poisonous nerve-gasses. They were extremely toxic and potentially lethal. Patients had different thresholds of when they reacted to the therapy and when it became toxic. Therefore technologies were developed in order to measure patients' experiences of side-effects. The first scale to measure the patient's nausea, fatigue, pain was filled out by the doctor on the basis of his interpretation of the

patient's well being (Fallowfield, 1990).

Right after world war II a number of other treatment technologies that required direct patient involvement was invented. For example speech-aid equipment for patients who had their larynx removed or stoma-packs for patients who had a cholestomi. The first patients' groups were also formed around these new technologies, but also a new psychosocial and pedagogical praxis focusing on psychological adaptation to life with cancer was born (Holland, 1990). To live with a larynxctomi one has to go through a special training and one needs guidance and advice from professionals, but also from other patients who have learned to live with this new technology. For these reasons groups of old patients were organized who trained the new ones. Innovation of technologies became in this way one of the starting points, not only for ways of client involvement, but also for a new social movement. But a movement with goals and means that went far beyond what can be explained only by looking at technological innovations!

Client perspective and the welfare state discourse of quality

Cancer cannot be cured. Its effects can be treated but often the treatment is much more painful and variable than primary effects themselves. This conflict is a challenge to the medical professional. In medical praxis the ideal is to cure or at least not to harm the patients or create more pain for them than before the treatment was initiated. These dilemmas make up the scene for a conflict of who was to define quality of treatment and ultimately quality of life and how these were to be defined. It becomes part of the welfare state praxis to relate to

this ongoing discussion of "what is quality and who is to decide?" This leads among other things to the development of technology of measuring quality of life and numerous ways of performing quality control. Clients perspective are for a number of reasons recognized and this recognition is in some way a very important part of the welfare state governance, but the active realization of this recognition is problematic. The client is seen as a customer or as an object, and activity is conceptualized in simplistic behaviorist or cognitivist terms. And the potential involvement is always questioned, and caught up in the dichotomy of subjectivity and objectivity between individual and group. Life conditions are always isolated and transcribed to factors.

Psychological theory plays an often tricky part in this process: Dressed up as a friend of the client or patient, but behind his back changing into a suspicious dark horse, objectifying, by aggregating all sorts of unconscious powers and by introducing an almost endless armory of theories of personality and disease, one's own responsibility for illness, emotions and health, and so on and so forth. These theories are problematic because they at one hand recognize that the patient plays an active part in his life, but on the other hand they do not overcome the individualism and objectification in traditional psychology and thereby potentially leave the patient in a pacified position between guilt and idealized hope.

The new concepts and technologies that are developed to describe and measure clients' points of view are problematic in a number of ways. They often only give indirect, interpretative, and partial access to perspectives. They also build on a fundamental but often implicit understanding of the person, not as a subject but a priori as a patient and representative of a diagnosis. There is also a tendency to decontextualisation: For

example the measure of experience of side-effect is seen as a general experience, no matter where the patient is and what she is doing. Only what can be decontextualised and abstracted from its societal and historical form can be recognized as (scientific) knowledge.

In the first part of this paper I have analyzed some examples of how clients' perspectives are recognized in praxis and how different concepts and technologies have been a part of this process. It has been pointed out, that psychological concepts and theories have played a problematic role in this process.

The next step is to take up the challenge of further development of concepts and theories from this critical perspective. The aim of such a theoretical work must be to make some kind of conceptual basis for the involvement of patients, not from a third-person, but from first-person or subjective perspective.

Understanding illness in praxis

This second part of the paper should be read as some preliminary questions and remarks towards a critical psychological theory of illness. The theory must be able to grasp and contribute to the development of conceptual tools to understand how we, in a subject active way, handle life with illness. In other words the theory must overcome traditional psychological individualization, privatization, and objectification of life with illness.

The first question that must be asked is: Do we really need a specific theory of life with illness? One could argue that there already exists a basic conceptual structure worked out in the framework of the science of the subject (Leontjev 1973, Holzkamp

1983, Dreier, 1993) that provides us with an understanding that reflects exactly the above-mentioned criticisms. So, let us first of all look at the possibilities and limitations of the theory of the subject in this particular context:

The theory of the subject provides us with a new perspective for understanding biological illness, not as a determinant or factor but as an aspect of the condition – meaning dyad in which action potency is developed and realized. From this perspective biological illness is not to be seen as a given thing, but as having a subjective meaning that is shaped, reinterpreted, etc., as a subject-active process in its historical societal forms. Living with disease, people are rarely entirely caught up in illness. People live in multiple action contexts in which different activities are conducted. We take part at particular places, occupying different positions, from which our perspectives can be understood. We actively take stands in practice, by reflecting our own and others' ways of participation, and we actively combine our moving around between different action contexts in the particularities and differences in our participation in a process of life trajectories (Dreier, 1993). Illness must be seen as an aspect of subjective action-potency and is as such changing as we change our position and move around.

But these concepts must be further developed in order to develop a psychology of illness. First of all, the central concept of action must in this particular context of illness be spelled out or qualified further. Action is defined in critical psychology in an almost residual way. Action is defined as a way to secure and widen action potency. As such the concept is very open, and of course action-potency is also a many-leveled business, involving a number of theoretical, philosophical, and even ethical references. It will never be a completely well defined con-

cept but is an ever on-going process of definition. The problem is that both in activity theory and critical psychology there is a tendency to look at activity as hierarchical. One talks about operations and activity, and, in critical psychology, about operations and action. It is an open question whether there still is a tendency in this tradition to subordinate different kinds of activities, abstracted from the actual praxis, where the activity is performed. It seems a bit beside the point to look at the activities of people with lethal diseases and severe handicaps, who are constantly living with pains, nausea, functional disabilities, extreme fatigue etc., with the same ideals of ongoing widening of action-potence. One is in some way caught up in or constantly lead to relate to one's biological function or dysfunction and perhaps activity has another structure in these situations. The ideal of ongoing subject-active securing and widening of action-potence is challenged when dealing with people with severe diseases. It is reasonable in this situation to ask whether this definition in fact represents an ideological reminiscence from a modern evolutionist ideal of "man climbing the staircase to ever higher levels of perfection, personal growth" etc.

Though I think there is some truth in the proposed critique of ideological over- or under-tones on part of critical psychology, I do not find it so compelling as to lead to a complete denial of the theory as such! But one has to take account of the fact that dealing with severe disease challenges the theory in a way that might be used to develop the theory in a constructive way. From this point of view it is even more interesting to look at Klaus Holzkamp's latest work on everyday life and the conduct of life (Holzkamp, 1998), because some of the same considerations of the overlooked or forgotten parts of life as mentioned above seem to be the starting point for his reflections: In

Klaus Holzkamp's latest works we find an unfinished draft of a theory of everyday life and conduct of life. In this article Klaus Holzkamp presents some preliminary thoughts on how to understand the question of how people live their everyday life and how they relate to biological changes, suggesting that a theory of action must be developed into more detailed theories of not necessarily subordinated levels of action, but of types of activity with a different structure, aims, and means. He deliberately separates "conduct of life" from terms like "life-style", "life-form" or "life-history". These latter concepts refer, according to Holzkamp, to esthetical and biographical aspects.

Holzkamp underlines the subject-active nature of conduct of life, but he emphasises that the subjective freedom has a relative character because it is always embedded in specific historical and societal conditions. He characterizes it as an ongoing subject-active process, and at the same time he stresses the functional nature of the concept: Conduct of life is to be understood as a necessity on an existential level. If we are not able to conduct our lives in an active manner, we react with anxiety. The routinized or automatized character of conduct of life releases me from the demand on stating conscious reasons for my activities: "I have washed my hair and dressed a million times before. I know it is such a reasonable thing to do, that I don't have to even think about it any more."

In his further discussion of the concept, Holzkamp also emphasises the cyclic character of the conduct of life. The cyclic character originates in the circular character of reproduction: Conduct of life has to do with things that have to be repeated over and over again: To eat, wash, sleep, etc. Conduct of life is a subordinated locus of structure that is the basis of all other fields of life's reali-

ties or action-contexts. In Holzkamp's words, it is the basis of everything, but not what life is really about. Real life is, according to Holzkamp, productivity, happiness, fulfilling of meaning, and collective struggle.

In this unfinished paper, Klaus Holzkamp raises a number of very important issues, but he also leaves us with a number of unanswered questions. First of all I think it is an open question whether it really is necessary to make this kind of a priori or general hierarchy of action/activity: Is it necessary to subordinate a special class of activity, and make it the basis of other, more real kind of actions? This in a way leads on to my next consideration: As Holzkamp stresses the functionality and necessity of the routinized character of everyday life, one has to ask if he is generalizing a "romantic" and in fact restrictive ideal of life in a specific socio-historical period?

A last critical comment is that conduct of life is described mainly as an individual project, its social or societal form is only mentioned as the way that one has to conduct life in a specific socio-historical structure of condition/meaning. But the social and societal function (or functionality) is not spelled out.

I will now try to be more specific in my critics and comments on the following themes in what way might conduct of life be functional in a non-individual way? Secondly, what does "relative freedom of action mean" when freedom is challenged by severe physical illness?

The social functionality of conduct of life

When theorizing on every day life, about the little things we do without noticing them, things that

are private and sometimes even taboo in our societal context, it is for obvious reasons difficult to overcome the tendency to think in individualized terms.

This might explain why Holzkamp's theorizing on everyday life primarily defines conduct of life as an individual project. It seems like the social aspect is only defined as the fact that we have to conduct life in a specific socio-historical structure. In order to challenge this stand one might ask: Could the conduct of life be functional in a social and not only individual way?

Although my body is mine and no one else's, the social form of conduct of life emerges at a number of different levels. Conduct of life is not only functional as an individual cyclic reproduction of ways of meeting bodily needs as a basis for attending other activities. It must be seen in a broader sense as part of social activity. In order to participate in different action contexts, some kind of synchronization of bodily function is necessary! The synchronization is not only biologically programmed, but can take many different conscious or tacit forms. At an extreme level, one can be forced into a restricted pattern of rules and rituals, on the other hand one might be in a position to choose a Rousseau-like "natural life" without restrictions and rules.

We do not have exactly the same bodies. They are shaped in different ways, have different forms and ages, and different functional problems. On the other hand we see each other as the same category of "thing" – as human beings, and at some level try to understand how we are feeling or "being" as human beings. We try to understand our own and the others subjective situation ("Befindlichkeit"). What Klaus Holzkamp has termed "the common stands of the subject" must in a way also reflect the ways in which we try to come to terms with the generalities and particularities of being bodies,

with its unique and yet well-known pain, joy, hunger, anxiety, etc. The psychoanalytic term of projective identification provides us with a phenomenological description of this "common" insight into "Befindlichkeit" or subjective situation of the other.

In other words conduct of life must be understood not only in its individual forms but also in its social forms, and as part of a larger structure of activity and aspect of the collective, and on-going process of becoming individual humans.

"Relative freedom of action" understood in the context of severe illness

Holzkamp emphasizes the subject-active character of conduct of life, but at the same time he points out that we always live with a relative freedom of action that is re-framed in an ever-changing societal and historical context: From a structural point of view modern society has developed a number of structures and institutions that create more or less flexible frameworks/conditions for the active conduct of life: Different technologies, such as clocks, timetables, the actual shaping of bathrooms, bedrooms, dining-rooms, kitchens, and a number of more-or-less visible or articulated cultural norms, habits, rituals, and taboos, make up the condition/meaning dyad for the subject. Furthermore the socio-historically developed conceptualizations and interrelated conceptual structures, discourses or thought-forms, establish more-or-less wide spread tools for recognizing and reflecting upon different elements of the process of conducting life. The subject is not entirely caught up in these structures, but the freedom is relative: On one hand "pain" cannot be recognized as "pain" outside the on-going pain-discourse (!). On

the other hand the meaning can be challenged, debated, and developed.

Klaus Holzkamp describes the active aspect of conduct of life in the way that one consciously makes this processes an object for reflection and change. This could be underscored even more by looking at the conduct of life as a "figure-ground" phenomenon or a configuration process. Instead of looking at conduct of life as something that, in order to fulfill its function, permanently moves a number of activities into the background, one could define conduct of life as a permanently or potentially changing figure-ground activity. Different bodily needs and inner perceptions are always in the picture, but can, by conscious action or by biological events, or by changes in position in time and space, change their character from part of the ground to part of the figure. The figure potentially calls for some kind of activity that could be conscious action or some kind of subordinating activity, like suppression, denial, forgetting etc.

This process will never be entirely determined by either biology or societal conditions, there will always be a relative freedom of action. The relativity of freedom is not only defined through historical or biological changes (aging, morbidity etc.) but has to be understood in its localized forms and related to specific action contexts in which it is embedded.

When a person is ill, the relative freedom of life is challenged in specific ways. The cyclic character of bodily function and the particular "figure-ground" relation between the tacit and conscious way we relate to bodily function is challenged in illnesses like cancer, where the cyclic character of reproductive activities might be completely disrupted. The figure-ground configuration process might be disturbed and sometimes even destroyed. The pain or other inner perceptions might be so overwhelming that the

picture is only an evil figure. If a person is "caught up in his or her illness" in this way, it is in a way even more problematic to talk about the conduct of life as the subordinated basis for real life. Does it mean that sick people do not have a real life? In a specific societal context, the loneliness and dependency are what characterize the diseased, and from outside – and sometimes even from the inside – it looks like "real life" has faded away. But if we look at the conduct of life as part of a process of trajectories, we have to be open to the possibility that the relative surfacing of biological processes might be interpreted differently or have different meaning in different action-contexts. Even the life of the diseased is structured in a number of different action contexts, and even the diseased have to connect and integrate these different "places" in meaningful ways. The focus on conduct of life might represent a way of regaining the subject-active grip on life in specific action-contexts, as when a group of chemo-therapy patients discuss and plan their diet and how to cope.

In some way the picture changes and what Holzkamp defined as real life and described as a vertical structure of events, in opposition to the horizontal, cyclic everyday life, is now in some way the horizon. Real life becomes the ongoing process. It is no longer meaningful to reconstruct this hierarchy of real and not-so-real life, abstracted from praxis.

Concluding remarks

In critical psychology the understanding of theorising of everyday-life has been overlooked. This is obvious when working with people with severe diseases. This group of people does not live an active life that can be understood in terms of ongoing fight for widening of action-potence. On the other hand, by accepting this kind of criti-

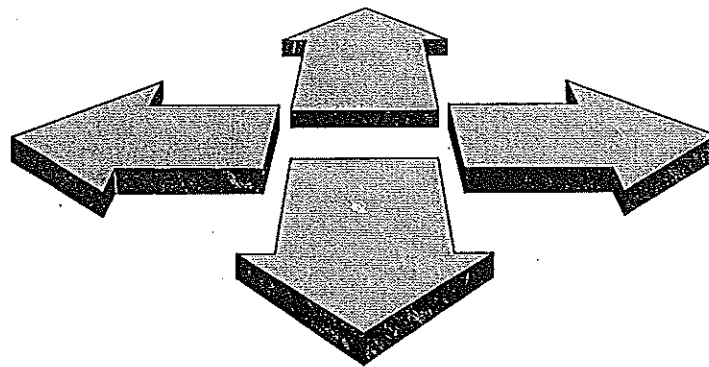
cism one easily ends up accepting the dichotomy and hierarchic structure of different aspects of life! It is easy to reproduce the tendency to individualize the conduct of life and to reproduce different kinds of subordination of forms of activity. I think it is a challenge to critical psychology to understand the every day life of the diseased – but in no way an impossible job, on the contrary critical psychology provides us with a theoretical framework that overcomes a number of problems produced by traditional psychology, but there is still a number of unanswered theoretical problems to overcome.

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