ORIGINAL ARTICLE

Understanding the meaning of rehabilitation to an aphasic patient through phenomenological analysis – a case study

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Abstract

Stroke patients with aphasia commonly suffer from distress related to their language deficit. They are often unable to express what they experience during their rehabilitation. Hence, the aim of this study was to reveal the meaning of rehabilitation to an aphasic person. With an approach based on the philosophy of Husserl and Merleau-Ponty, two open-ended interviews were analysed through the Empirical Phenomenological Psychological (EPP) method. The essential structure of the meaning of rehabilitation to the informant was that he lived as being responsible in a dichotomised situation. The informant had to adapt his behaviour, thereby destroying his chances of normal interactions; he was supposed to train in a goal-oriented way and believe in recuperation, but at the same time, he had to prepare himself and his next of kin for a failure. The defined impairment of aphasia misled both the informant and health care professionals to focus only language therapy, hence leaving the informant unsupported in other important aspects of the rehabilitation.

Key words: Stroke, aphasia, case study, phenomenology, rehabilitation

Introduction

A person affected by stroke has brain damage because of a focal infarction or a bleeding in the brain. The brain damage leads to a therapeutically complex situation where the patient, besides a bodily impairment, may be cognitively impaired and suffer from psychosocial changes. These changes can contribute to a negative self-concept because of decreased capability and independence and a sense of separation between the self and the changed body (Ellis-Hill, Payne & Ward, 2000; Ellis-Hill & Horn, 2000). The patient often gets depressed (Ytterberg, Anderson Malm & Britton, 2000) and may face a developmental or an existential crisis (Nilsson, Jansson & Norberg, 1999; Nilsson, Jansson & Norberg, 1997). These complex problem usually cause a decrease in the patient’s quality of life and a need of psychosocial support; a fact that has been repeatedly demonstrated in research from the early beginning of the 1980s to the early beginning of the 2000s (de Haan, Limburg, van der Meulen, Jacobs & Aaronson, 1995; King, 1996, Mayo, Wood-Dauphinee, Cote, Durcan & Carlton, 2002; Ahlsio, Britton, Murray & Theorell, 1984; Glader, Stegmayr, Johansson, Hulter-Asberg, Staaf & Wester, 2001). Hence, the need for a deeper understanding of stroke patients’ psychosocial experiences and needs during rehabilitation seems to have been evident for two decades.

Among the constellations of cognitive damage the damage of the spoken and written language, aphasia, is an important subgroup. Aphasic stroke patients experience predicaments in life that are caused by their language deficit, and which are not found among stroke patients with normal communication (Doyle, Mcneil, Hula & Micolic, 2003). Aphasia has also a specific, negative influence on quality of life in a long-term perspective. Furthermore, the patients’ experiences are individual, complex and changing during the different phases in their rehabilitation (Parr, 2001).
Hence, there are good reasons to make aphasic patients’ experiences of rehabilitation understood by their carers. By “understood” the authors of this paper mean that the patient’s damaged speech is transformed to an understandable language and the meaning revealed of the experiences that the patient is trying to communicate. This focus on the patient’s experiences during the rehabilitation is as important to the patient as the training of the specific deficit of the language (Ross & Wertz, 2003). Such an understanding of the patient might supplement present knowledge of how to support aphasic patients across barriers in social transactions and of the importance of communication through alternative means when words cannot be used at all (Andersson & Fridlund, 2002; Sundin & Jansson, 2003).

In an ongoing study on persons who recently had had a stroke, a man who had become aphasic was included. At the time of his stroke, he was in a quite active period in his private and professional career. That he was aphasic meant that he in his speech confused words both when he listened and when he spoke. For that reason, although he was difficult, often impossible, to understand, the researchers had a fractioned impression of what he tried to say. This made them think that the informant’s experiences might somehow be understood and communicated by means of a qualitative method. Earlier studies, as mentioned above, have increased our knowledge about aphasic persons as experienced by their carers, barriers to their social integration, and their experiences described in retrospection. There is, however, still a need for studies that give voice to aphasic patients’ experiences during rehabilitation (Hafsteinsdottir & Grypdonck, 1997; Lloyd, Gatherer & Kalsy, 2006). Hence, the aim of this study was to explore what rehabilitation meant to an aphasic stroke patient.

Method

“The case”

A case-study approach was found suitable, given the aim of the study. A case-study can focus on a specific person or situation, gives a good description of a phenomenon, has an heuristic value and allows an inductive approach (Merriam, 1994). The chosen informant was a 58-year-old man. He had a position of expert in an international logistics company. His occupation was intertwined with his hobby activities, and in both respects an absolutely intact language was a demand. Within the hobby activities, he was engaged in both a national and an international organization as a leading expert. His mother tongue was Swedish, but he was fluent in English and German. Three months before the first interview, the informant, while he attended a conference in a foreign capital city, had a cerebral infarction in the left side of his brain. The infarction had affected his spoken language and his perception of words and numbers, but had left him physically almost untouched.

His speech is demonstrated in the following example from the beginning of the first interview. This and all the following quotations are translations from Swedish revised by a native English-speaking researcher.

I have been affected by eh eh I have been affected yes I cannot say the word but eh I cannot talk about man—right myself. I lost my up ... my way to describe what happened to myself and talk about the background to myself. It is called oh it is it yes the word cannot ... yes hum and it happened very quickly but it happened a little before I fell ill, I didn’t quite notice it. So that two or three days before I was in X-city I felt that I couldn’t manage exactly, but the day before the day before then I had had in meeting and then I had forgotten yes I knew that it was meeting but I couldn’t describe but I knew the time when I should count on X-city back. I knew exactly so I recalculated everything from that and went home.

Or, as described by the informant’s speech therapist:

The patient has a severe aphasia with great impairments in all domains. The speech is fluent with abundant literal paraphrases and neologisms. // The comprehension is severely impaired. // Can write his name, but as for the rest he writes totally neologistically.

Methodological considerations

We wanted to reveal what rehabilitation meant to the informant such as it was lived by him. The meaning should thus be revealed from his experience of rehabilitation still in progress. However, the informant spoke with the use of neologisms and omission of correct words and often misunderstood what was said. An interview-transcription would mirror these difficulties. Therefore, when choosing an appropriate research approach, the researchers had to consider both the research-philosophical frame for searching for a meaning expressed through an obscure language and the method of analysis integrated in the chosen research-philosophy.
As for the research-philosophical problem, a phenomenological approach was chosen. Phenomenology, first described by Husserl (1989; 1992), is a philosophy about how we, as human beings are related to the world. We are immersed in the lifeworld and we cannot separate ourselves from it. We are present in this world as perceiving beings and our consciousness is intentionally directed towards the phenomena in the world in which we are. Phenomena are experienced in a natural, un-reflected attitude. However, we give perceived phenomena some sort of a meaning and it is through this meaning that they are present in the human world. Anything else is transcendental. Hence, it is through the perceived, un-reflected, lived experience of a phenomenon that the researcher should begin the research. To perform this, the researcher should leave out pre-understandings of the phenomenon in a process of “bracketing”. The collected complex of experiences of the phenomenon can then be described in a comprehensive structure and by means of imaginative variation, and eventually, be presented in an essential structure of meaning of the phenomenon. Husserl, however, described theoretically how to reveal the meaning of a phenomenon as such. He did not give the descriptions of how to perform empirical research.

The French phenomenological philosopher Merleau-Ponty (1994) took a further philosophical step, relevant to the present project. Merleau-Ponty described how we can be in the world only as beings in our bodies, not as bodies in the world but intertwined in the world in our bodies. We communicate with the world through our bodies within the world in togetherness. Through togetherness, not by being observers, we can have an understanding of the reciprocal experiences of each other.

Hence, the philosophy of Merleau-Ponty bridged the gap between the research-philosophical and the analytical problem in the present study: A brain-damaged person, like anyone else, is to find in his or her own body and his or her thoughts are to find in the way he or she expresses them in constructions of words. When the brain-damaged person moves he or she cannot make the smooth movement of a normal person, because the damage forces him or her to move in fragmentations of misdirected steps. However, in a shared world, another human being can still see the intended direction and the goal of the entire movement, the meaning of the movement. It was a similar situation in our encounter with the aphasic man in the present study. He was in his speech, but he had simultaneously to concentrate on how to find words and construct sentences, which made his speech stepwise and marred with verbal and semantic errors. As partakers in his world, though, we, as researchers could reveal the intention of his speech and thus to a varying extent what he expressed. The condition, however, was an analytic step through which the informant’s speech could be thoroughly observed.

The interviews

The informant was interviewed twice by one of the authors (FH). The first interview was performed three months after the stroke at a community rehabilitation centre and lasted 60 minutes. The first and foremost interview question was, “What has happened to you?” In previous interviews, this question had proved important to the informants as a starting point for narrations of their lived experiences after a stroke. It was supposed, therefore, that this question had a strong impact that it would be understandable even to the aphasic informant. After hearing the first question, the informant spoke freely and vividly. The interlocutors often involved themselves in an open dialogue in a mutual attempt to avoid misunderstandings. The interview was tape-recorded and later transcribed verbatim as a text by the researcher (FH). Besides the understandable phrases and words, incomprehensible phrases, neologisms, wrongly used words, incomprehensible phonemes and expressions of affection were also included in the transcription. The second interview was carried out nine months after the first, as a follow-up of the meaning of the lived experiences of the rehabilitation process.

The analysis

The analysis followed the Empirical, Phenomenological and Psychological method (EPP) according to Karlsson (1995), which has strong similarities with the principles of Giorgi, but allows for interpretation (Giorgi, 1997). This empirical, phenomenological method, used in psychological research, searches to reveal the meaning of a phenomenon as it is lived. It follows to some extent Husserl’s principle of active efforts to “bracket out” the researchers’ theoretical pre-understanding in the first steps of a text analysis. The “bracketing”, however, does not exclude an empathetic, psychological focus in the analysis on the experiences of the researched phenomenon as it is lived by the informant and what its means to her or him. The attitude of the researchers in the present project might conveniently be described as a “bridling” of the pre-understanding (Dahlberg & Dahlberg, 2004). Hence, applied to the present study, the EPP method meant that the researchers tried to get an empathetic understanding of the text. They did not apply their professional knowledge about what it
meant to treat an aphasic person in rehabilitation. In consequence, the voice of the informant and what he conveyed was left undistorted by the pre-understanding of the researchers in the first steps of the analysis (Levasseur, 2003).

Four of the authors (CB, FH, HK and SK) did the analysis. The analysis was done stepwise in five steps. First, the text was read several times to get a good grasp of how the informant spoke about the researched phenomenon. In this step, theoretical reflection was withheld according to the above-mentioned principle of bridling. Second, the whole text was divided into meaning units. A meaning unit could be a whole paragraph or one single word. The text was marked every time a shift in meaning occurred. Third, the informant’s personal language was transformed, unit-by-unit, to the researchers’ language. For example, the original text in the quotation above was transformed to

S cannot use verbal expressions.
S cannot express information about himself to others.
S cannot name his condition.
S cannot behave normally in a foreign city.

The researchers discussed the transcription unit by unit. When different interpretations occurred, the researchers returned to the interview text and discussed in a free, imaginative process until agreement was reached in a negotiated consensus. Fourth, the text was gone through in a search for comprehensive themes. The text was interpreted with connection to the researchers’ theoretical knowledge in an interchange between the original data, the transformed units and the researchers’ theoretical pre-understanding about rehabilitation. The meaning units were assorted into appropriate themes and thus made up a general structure of the phenomenon. The essential structure penetrated all the revealed themes and thus the meaning of the researched phenomenon to the informant. The method in these three final steps was influenced by the reflections of Giorgi (2000).

### Ethics

The Karolinska Institute research ethics committee North approved the project (§00–359). The informant was in a stressful and frustrating situation, which necessitated specific ethical awareness of the interviewer. Research interviews might have therapeutical implications. This had to be considered during the interviews. After the interviews, the conversation continued and the interviewee could ask questions and have them answered until he expressed that he was satisfied and wanted to finish the meeting.

### Findings

In this section, the five themes of the general structure will be described under separate headings, illustrated by quotations. Finally, essential structure of the results will be described.

#### Themes

1. **Lost expression of oneself as a thinking and acting person.** The informant described how the loss of normal language hindered him from expressing himself as a thinking and acting person in everyday life. To be as a person together with others meant to convey a perception of who one is. However, the informant was unable to describe coherently to others how he was changed after the stroke and thus he did not exist face to face with others as the kind of a person he actually had become. Every day life was a life full of events and plans in a togetherness. The informant had many plans and many events took place in his life, but he could neither give other people a varied description of what had happened to him during this everyday life, nor let them share the thoughts, that these events had created in his mind. Hence, in spite of many close relations, yet, he still remained outside.

//Yes but this being able to do the reality not being able to tell yourself what has happened... and what problems I have myself. What I actually can tell about different bits there I miss enormously much about what the reality is eh... myself. Well, if you understand what I mean what I cannot sa- a yes not a different word which system actually has happened to me eh.

Furthermore, to be in a rehabilitation process for an impairment of communication, meant, in the informants view, to communicate in a natural way, like normal people in normal conversations. Yet, dialogues with other people became unnatural and
tense, because the risk of misunderstandings forced
the informant to check repeatedly what had been
said. This checking behaviour was, however, con-
trary to the natural behaviour, which he thought a
prerequisite to be rehabilitated as the person he still
was. Hence, he tried to behave naturally, and it did
not work.

// how can I now do myself to tell things correctly
so that my wife doesn't get mistakes . . . we go the
luncheon just a moment ago and she has said that
we just should meet on that side and meet and she
sat down on the other side. Yes and we had not
mastered where we should meet exactly.

2. Adapted behaviour. Hence, the informant had to
change his behaviour to be understood and to
understand. He had to behave with what he in his
changed language called “caution”. When other
people communicated in a natural and simple way,
he was forced to concentrate not on the conversa-
tion, but on the fact, that he had become different
from them. Although, he had always considered
himself a careful person, it was now necessary for
him to be scrupulous to the extreme. He thought
that he ought to make other people understand this,
but he could not give them this understanding
because the very introduction of his predicaments
in a dialogue disturbed the transaction. The normal
flow of the conversation was broken and the con-
versation became abnormal. The informant consid-
ered himself the deviant person. Therefore, he
thought that it was his obligation to change his
behaviour. It was not the others that should adapt
to him.

... and in this way I will have and then I must
change my own way of thinking of it eh. I must
change . . . I must change all the time . . . it is so
easy to scramble by . . . easy for you eh yes and
then says obviously it is obvious to me that my wife
says like this. M-yes I feel that I have an enormous
need. It is I who am the deviant in most of the
others.

3. Rehabilitation in the personal network. The infor-
mant found that the prerequisite for a successful
rehabilitation was an active social engagement with
family, friends and colleagues. He appreciated all
contacts with other people, found them valuable to
his rehabilitation, and frequently used the expression
that he “had to be open”. However, daily intercourse
meant embarrassing misunderstandings, especially
in relation to those who were closest to him. He
found that he had an obligation not to be embarras-
sing to them and to see to it that embarrassing
situations would not dominate everyday life. Overall,
he thought that he had to give his nearest and dearest
an optimistic picture of his rehabilitation prognosis
and his vocational future. So far, he thought that
openness about his situation was important.

... so I can talk about this you know it is a great
advantage to me eh who has this kind of people
around me you know. That I have felt very
important to open. Openness to everybody. Try
to get right without being difficult . . . so that I
don’t just blow it away like this and say: Ah I
cannot say ‘read’ then and then and then not a
word eh?

Simultaneously, however, openness meant that it
was his obligation to prepare his next of kin for the
possibility that he might never regain his former
language completely.

// so that you so that not forget to learn yourself
completely that I am afraid of such situations that
it can go wrong. Then it is better to have open and
talk to all people, even comrades.

4. Rehabilitation in the professional network. The
informant found training together with a speech
therapist extremely important as an activity parallel
to his own practice. However, he described with
contempt how he initially after the stroke had been
observed by his therapists. He demanded to be met
through dialogues that gave him relevant conver-
sation, support and stimulation. Certainly, he under-
stood the professionals’ way of working, but he
found it could be done in a more conversational
and descriptive way that involved him as a person.
The dialogues with professionals should involve him
in what was going to happen in spite of his
incapability to understand all that was said. The
only professional he considered had lived up to these
demands, was the speech therapist.

... yes eh it’s maybe more both things together eh
in the beginning // but testing that is as if I felt
mostly a bit disturbed // and then just leaving you
to show it eh while I am thinking it is better to talk
about it eh // it was kind of another way of being.
Bigger ways in which to ask questions (i.e. the
speech therapist), ask about different issues,
method to work with and discussions with us too
eh; but with her directly that like this showed told
about the background.
5. Rehabilitation as goal direction. The informant endeavoured to regain a language good enough to get him back to his job. He thought that a goal-oriented behaviour was the prerequisite for this. If he did not work continuously with his predicaments, he did not expect them to be overcome. Goal-oriented practice implied that he had to look positively on his prognoses, but simultaneously, he had to be aware that he had to prepare for a possible failure. Hence, he introduced hope as part of the support for being goal orientated. He described hope as a truism in rehabilitation. It would be impossible for him to continue the rehabilitation if he could not hope for a return to the life he had had before the stroke. In his encounters with professionals, he had found most support for his goal-oriented struggle in the speech therapist’s training programme, but only if the programme gave him encouragements through successful results. He would not be discouraged by difficult exercises that caused failures.

// but if you don’t grasp it, you won’t get anywhere. So, you work with the question and struggle//.

As a result, in the second interview he eventually focussed on hope for recuperation and not on how to be prepared for alternatives to recovery. When he described the encounter with the physician at the Department of Rehabilitation Medicine, he seemed to have been surprised when the doctor told that he might not recuperate and the doctor instead talked about retirement.

//then he said that ‘you must count on that you never get well, there is a risk that you won’t get well’. Yes but I cannot think in this way, I said, I must have a goal. I must manage although I know that I don’t achieve completely, but I must get through some bit and do things. ‘Yes but you must be prepared for that it might stop.’ Yes but not yet at least, I said. I have still the same demands on myself that I’ll do a lot of things between . . . .

Essential structure

To be goal-oriented in a life of dichotomies. To the informant rehabilitation meant to behave in a goal-oriented manner towards recuperation, balancing between dichotomies. He struggled to achieve the goal of natural social encounters without embarrassing misunderstandings. Avoiding misunderstandings required adaptations to people around him. However, adaptations made the encounters unnatural and misunderstandings were not avoided after all. He found it necessary to train at his language beyond the prescriptions of the professionals, if he was to improve. Therefore, he required difficult exercises. However, he had to define and abstain from tasks beyond his actual capacity, because failures had a discouraging influence. If he were to endure the tough task of being in a continuously ongoing practice, he had to believe that the practice would bring him back to his former life and, alternatively, he also had to prepare for the situation that might occur, should he not achieve this goal. Hence, he had to prepare for conflicting outcomes and at the same time be both optimistic and realistic. The informant thought that he and not his next of kin or the professionals had to carry the full responsibility for the rehabilitation process, balancing the dichotomies that were caused by his impairment. He had the responsibility for adapting to avoid misunderstandings with those close to him. He had to make those close to him believe that his lost function would return and at the same time prepare them for the possibility that he might not regain his language. He was the one responsible for choosing demanding exercises that would improve his speech as well as exercises that did not exceed his actual capacity. He was obliged to control this comprehensive process between the dichotomies.

. . . that I cannot ask someone who usually works on these things that they take me over and think everything I but I must try and describe for other person . . . and I . . . I have gotten better after that in the hospital so now it works better and better and try do something . . . but suddenly practice, practice, practice I that I feel it’s alpha and omega to get somewhere.

Discussion

Rehabilitation after a stroke meant to an aphasic man to practice in a goal-oriented way towards his former language ability and his former life in a balance between dichotomies, as he also had to prepare for a life with everlasting impairment.

The study revealed how the categories of meaning, to strive towards a goal and to manage the tight rope act between dichotomies were imbalanced both for the patient and for the system that supported him. Svenaeus describes, from phenomenological philosophy, the meaning of a stroke as an experience of a body that becomes “uncanny” (Svenaeus, 2000). Our body is our home in the world and its intentional functions are “the tools” that gives us a projective, intentional power into the world. In illness, the “tool” is broken and we are hindered from acting as we did before. In dialogues with
health care professionals, the ill person probably needs to reflect upon the body both as a biological damaged tool and as a tool that expands into its comprehensive context and gives future a meaning. To a stroke patient this often means that she or he has to manage a complex of motor and cognitive impairments, and therefore, she or he has to manage quite different acts in the spatial world. The patient of our study, however, had a well definable loss of his language. Hence, he could act autonomously in the spatial world. Yet his body’s tool for access to the world of human relations was damaged. This very well defined loss turned the focus of the meaning of the rehabilitation to a simplification: repairing the language.

Andersson and Fridlund (2002) describe how aphasic patients need their carer’s support in interactions to make them feel secure and get a feeling of ability (Andersson & Fridlund, 2002). Otherwise, they may lose self-esteem and get a feeling of being outsiders. Our informant, however, plunged, as he was used to, into a variety of social contacts, although his efforts did not work. Parr talks about the importance to aphasic persons of having carers that can listen to their individual, complex interior perspective (Parr, 2001). The interior perspective of our informant became the simplification, that language restoration was the meaning of his rehabilitation. Hence, he found a speech therapist that treated him according to this perspective and the dichotomies in his rehabilitation were not considered. He had reflected upon the possibility of different outcomes of his treatment at the beginning of his rehabilitation. These reflections were not grasped in his rehabilitation context until the latest encounter when his pension was discussed. By that time his initial understanding, that rehabilitation might mean reflection about different outcomes, had faded.

In retrospect, aphasic patients have described how the most devastating effect of aphasia is its effect on interpersonal life (Nystro¨m, 2006). They suppress feelings and feel alienated and frustrated. Nyström emphasizes that patients with aphasia have a need to express these feelings and they should be helped to communicate them. Our informant’s relations to his loved ones were frustrated by misunderstandings and conflicts. He could talk to his speech therapist about communication as such, but he also seemed to have a need for a conversation partner who could receive and understand the dichotomies he met in encounters. The narrow scope in the meaning of rehabilitation implied scarce contacts with professionals that had the competence to penetrate and open the possibility of coping with frustrations.

The damaged language was a hindrance to an understanding of his life in dichotomies between him and his next-of-kin. A carer with experience of aphasic care and the competence to create an understanding and caring communion that involved his relatives was missing (Sundin & Jansson, 2003). This kind of treatment, separated from mere language therapy, might have made it possible to lower his distress (Hilary, Roy, Byng & Smith, 2003).

What a patient seeks in the patient-physician relationship, explains Toombs, is a unique kind of “face to face relationship” to convey the meaning of illness in the context of a particular biographical situation (Toombs, 1993). Not just to have the tool repaired, but get the broken tool to work in its totality of relevance. Our informant expressed this but this meaning was hidden by his defect language in an ordinary consultation. The interpretation of his speech, that rehabilitation meant training, prevailed. Hence, our study revealed that the informant during his rehabilitation had a need for a reflected understanding of what rehabilitation meant to him when all his experiences were included. His professional contacts seemed to have had the same need in order to know how to expand the scope for their support. To find the means to make this kind of individual experiences integrated in the planning of professionals seemed important.

Our study had limitations. In the interviews and in the reading of the written text many single words and many passages were ambiguous. Therefore, misunderstandings occurred and the richness of the studied data could not be used to the same extent had the informant been able to communicate normally. Hence, the analysis of the findings achieved less diversity of shade compared to an analysis of the speech of a person without aphasia. However, in view of the incomprehensiveness of the informant, the authors considered the findings comprehensive enough. The chosen philosophical approach and the analytical method were important for the findings, although they implied both advantages and pitfalls (Merleau-Ponty, 1994; Karlsson, 1995). The problem of how to bracket or bridle the pre-understanding of a researcher in the confrontation with an unclear text was obvious. The risk of lost distance to what the data told increased because of the lack of transparency of the text, which may have lead to over-interpretation. To minimise this risk four researchers were involved. This meant a reciprocal process of mutual learning, reflection and negotiation. To this was added the control of a co-reader (IH).

During the analysis, the stepwise construct of the method had to be followed meticulously. The risk of interpretational shortcuts in this step was evident.
With reference to the philosophy of Merleau-Ponty, the authors found that the method revealed the intention of what the informant tried to say and what it meant to him on a deeper level (Dahlgberg & Dahlberg, 2004). An analysis of this kind was as crucial to the rehabilitation of the aphasic person as the focal anatomical diagnosis was for further treatment of the body and the linguistic diagnosis was for the treatment of the language. A qualitative method applied to single encounters might help professionals to understand what rehabilitation means to the patient and guide them to act in accordance with this.

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