

PP 01

**“One thing I’ll never do: To give up”!**  
**Children with cancer in the final stage and other diseases.**  
**An educational approach to existential situations in human life.**  
*Research in the 21<sup>st</sup> century”*

I want to thank Professor Takeda for the invitation to this international congress and I wish the Forum an outstanding result for the scientifically and practically research in this sensitive and existential field.

PP 02

Cologne is situated in the heart of Europe. It’s famous for its Cathedral ‘Koelner Dom’, but for its University and with the biggest Department of Heilpaedagogik (Remedial Education/Special Education) in Europe too.

I have just finished a more then thirty year work at the University of Cologne in the field of ‘Heilpaedagogik’ (Remedial Education/Special Education). From **this background** I’d like to approach the theme of the Forum in my presentation. It will **frame** in a sense **the specified contribution** from the national and international experts in the field of medicine, education and care.

The presentation consists of three parts:

Part I includes information about Cologne

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I. A holistic view on the local situation of children with cancer in the city of Cologne

Part II connects our world-experience with the existential situation of the children.

II. An unknown dimension of our ‘world-experience’

And part III offers a model which may help to deepen our understanding of this existential situation.

III. ‘Theory U’– a way of exploring profound change

I finish with a conclusion remark.

Conclusion remark

For making this condensed presentation possible I need **your** open mind, open heart and open will of understanding.

PP 04

(1) “One thing I’ll never do: To give up!” is written on the rainbow coloured bracelet of the German Children Cancer Foundation (PP Armband) and Sven-Hendrik, a boy who became only 11 years old, presented in 1996 to the housewarming of the Parents-House on the University Hospital Campus in Cologne a picture saying (2) “Only bats let themselves go” (PP “Nur Feldermäuse lassen sich hängen.”) i.e. “let themselves hang down” i.e. in German ‘don’t fight’.

(3) Children make clear what (4) **life** means for them.  
How does the **network** around these children **respond** to their needs?

PP 05

## I. Holistic view on the local situation of children with cancer in the city of Cologne

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### Campus and school for ill students

On the clinic campus you find a school which is called ‘School for ill students’ (Schule fuer Kranke) or ‘Hospital school’ (Krankenhauschule). Formally it is **one** of ten special school types in the school system of the Federal Republic of Germany.

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### Hospital school / Johann-Christoph-Winters

(1) The name of the Hospital school is ‘Johann-Christoph-Winters’. The school – situated in different parts of the city – it is also called a ‘Special school in the university clinic’.

The law says: If a child will be ill for **more than four weeks** it has the right and the duty to visit the school for ill students.

May be from here derives the **motto** of the ‘Johann-Christoph-Winters’ school:

#### Motto

(2) **“The ill child needs therapy, because it is ill. And it needs education, because it is a child.”**

Two groups of children and youth going to this school are focused:

(3) The first and the bigger one are students with ‘mental and psychological’ problems, about one hundred pupils in a year, trained in a special school building or in special places in different clinics.

The other group are students with ‘physical’ problems like those with cancer, dialysis and mucoviscidosis patients or those with cardiologic problems, except transplantations.

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### Campus

The children oncology ward, day clinic and ambulance are admitting about sixty to eighty patients every year.

Forty of them are visiting during the year the school. About twenty are taught every week.

There are supporting measures around the school:

The children, their parents as well as the teachers are supported in the hospital by a psychologist and a social worker. All persons engaged with the children are forming a network of cooperation, also with the mother schools or when the children need support at home during specific rehabilitation. Located on the campus is the so called 'Parents home'. Not only as a place to stay for parents in 15 apartments but also with a variety of activities it has a very specific function on the campus for parents, children and the clinical staff too.

It can also be mentioned, that just now the department for cardiologic treatments of children starts cooperation with the children oncology, because they discovered mutual problems about they could share opinions and experiences.

The same concerns with the Mildred Scheel house, hospice home for adult persons, situated near the departments for oncology and the Ambulant Children Hospice Work in the city of Cologne.

Coming back to the school:

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(1) For the children with cancer the 'Johann-Christoph-Winters' HOSPITAL SCHOOL offers for the twenty students every week reduced lessons from primary school until junior high school age with the support of three teachers, one of a special school and two of normal schools.

(2) Classes are given as bedside teaching, or in one therapeutic room or in the classroom on the basement floor. Mrs. Breidenbach – one of the three teachers - is teaching there already more than sixteen years.

As she told me the contents of the subjects follows the curriculum of regular school classes. The main subjects are math, reading, writing and foreign languages. One lady as an art therapist works specifically with the children in this field. - Children under the age of 6 are cared by a Kindergarten teacher in the oncology ward.

The background why I speak of a **holistic** view is the strong **network of cooperation** between the different groups.

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But somehow the school for ill children is an 'educational-ecologic niche', as Mr. Oelsner, the director of the Johann-Christoph-Winters-School puts it in a conversation. The school belongs to the special school system. Beside besides utter barriers like the distance to the mother school, the lack of friends or bodily consequences after the medical treatment which make it

difficult for the children to return to their former classes – it is also not easy because of the formal character of the school as a special one.

Here I should make a critical comment to the school system in Germany which interpret children as exceptional and which developed for them ‘special schools’. This is not the right way. Though the child needs therapy and care because it is ill, the school for ill students could and should be more included in the general school system and especially in the general consciousness of the society.

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In Cologne the classroom **in** the hospital signalizes and symbolizes that the students belong to the general school life.

Let’s take once more a short and specific view on teaching these children. It might be typical, that the main subjects taught to them are those with more objective contents: Math, reading and writing or foreign languages. The importance of these subjects in normal school education and therefore also in the school for the ill students is without doubt. But the given **moment**, the **here and the now** of the diagnosis cancer produces an inevitable **tension**. Though art therapy, close connections between teachers and students allow a deep understanding and empathic relationship, **the question what education in life threatening situations means is difficult to answer**.

For children who are hit with the diagnosis of cancer isn’t it paradox to learn abilities for **tomorrow** and for teachers to teach them and to talk with them about the **future** not knowing if there is an **evening of today**?

Might this be one reason that the fluctuation of teachers, teaching these children in Japan, is high as the research of Takeda shows: 77% of the teachers finish their work before the end of the three years period? Could one say that the problem of teaching children with cancer is a problem of teachers – too, so that children **and** teachers –and all other experts - are connected in an exceptional situation? And if it is a problem of the teachers, what might be the reason for it?

There are reasons which could explain this:

- the tabu in public awareness;
- the lack of the theme in teacher training programs at Universities and Colleges and conceptual vagueness in school structures; and last but not least
- the existential situation;

Are these real or the only reasons for explaining the above fact? Or might be hidden behind this experience a deeper source which makes it difficult to deal with the different problems? And could this deeper source guide us to a new approach to existential situations?

This is my hypothesis which I want to follow in part II, which tries to transcend the given situation and asks how to develop new views.

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## **II. An unknown dimension of our world-experience**

The crucial point in the situation for children with cancer and their parents, doctors, nurses, teachers and people of social services is:

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With the diagnosis cancer one aspect inundates absolutely life – it's **time**: The unknown dimension of time and the possibility of an inescapable **limitation of the child's 'life time'**. Looking with the 'chronometry' i.e. with the 'watch' at the life situation of children with cancer there only can follow *helplessness or desperation*. Very often called: 'Fighting against the time'.

When we hear 'time' we connect it mostly with the so called 'watch-time' which is **measured** in seconds, minutes, hours, days, weeks and years and so on. But can we discover another dimension to deal with this situation? L

Listening to the cultural philosopher *Jean Gebser* '**time is the sign of the 20<sup>th</sup> and 21<sup>st</sup> century**' but **not** in its 'spatial quality' as measurable size like the watch-time but '**time as intensity**'. For *Gebser* **time is intensity**, it is a **quality** – not only a measurable quantity:

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**Time**

"Time is (of course also) time of the watch, but beyond this time is time of nature, cosmic time or time of stars; its biological period, rhythm, metric; mutation, discontinuity, relativity; vital dynamic, psychic energy, mental dividing; time expresses itself as a **conscious unit of past, presence and future**; time is creativity, imagination, work, also motor activity." (*Gebser* III, 382; V/I, 168)

Being involved to work and live with ill children means to realize this quality of time. When **time is vital, biologic, psychic, social or cosmic intensity** – which means to be not bound to the 'chronos' but liberated **from chronos, a-chronos** – then **time for children with cancer** can be translated as:

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**Time for ill children**

*'Time of losing hairs because of medical treatment; time as the body condition after chemical or radiotherapy and being touched by warm hands; its dreaming and anxiety in the night; its joking and laughing, its being connected and being treated as a partner through participating in the transparency of knowledge of the experts about the child daily changing situation; its flying to the sky and touching the earth – as the swallow and the girl'* on the Congress Poster do.

We as teachers are confronted with this 'time', which means we have to try to understand this intensity of life, to include it in our teaching and education. Doing this means to realize the

**unit of past, presence and future.** Understanding this shift opens us a not yet experienced aspect of our **human existence** and the **future tasks**.

I must omit to introduce to you detailed *Jean Gebser* (1905-1973). He is not yet known in Japan. I found only two researchers - Mrs. Professor Ikeda Richiko (International Christian University Tokyo) and Mrs. Professor Isa Masako (Okinawa Christian University) who studied his work and who mention him in some articles.

Only these remarks: In his elaborated evolutionary model *Gebser* identifies four major configurations of consciousness in our collective past through which whole cultures and epochs have their distinct style of thought and life. He named the following four structures of world-experience:

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(1)

- the *archaic* structure
- the *magical* structure
- the *mythical* structure, and
- the *mental* structure.

In his monumental work **The Ever-Present Origin** he illustrates, “that we are currently **witnesses** to, and **participants** in, a fifth major organization of our cognitive field” which he calls

(2)

- the a-rational or *integral* structure of consciousness.

(3)

For *Gebser* modern consciousness is an **inter play** of all five structures.

What does it mean when we connect the integral structure of consciousness to education?

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(1) **Education**

*Gebser* wasn't an educator. Therefore we don't find a 'direct translation' of his 'archaeology of consciousness.'

*Georges Pfeiffenschneider* (<http://www.integraleweltsicht.de/Transparente-Welt/index-transparente-Welt.htm>) offers such a translation into the field of education. I follow his description how he demonstrates the influence of a new **integral world view** to **education in general** and what this could mean especially for **ill** children.

The following aspects are quite shortcut and they can't be more than impulses in which everybody has to put new life in by himself. Selected aspects are:

## (2) Processes

The integral consciousness allows students and teachers to be included in the process of life and work. All doing, growth and fade, has to become transparent or 'diaphan' as *Gebser* says.

For **ill** students it could mean just not to cut them off of daily life, also not of the daily life in the hospital. The child should know about everything what happens with and around him. This means to keep contact with the whole team in the hospital and with the mother-school too.

Every day has a beginning and an ending. Every encounter starts and finishes consciously with the beginning and the end. In all subjects should be included the aspect, that our world is not only an object outside of ourselves but depends on us – i.e.: the world **is our creation** and what we find in the world is a **construction of man**.

Beyond this experience it is also important to let the children **participate** in:

## (3) Primeval Experiences

It means to dive in aspects of our magic consciousness through which we realize through all our life the unity with the world. These experiences doesn't mean to go (only) to leisure parks like Disneyland. These modern places of diversion may allow superficially the same physiological reactions but they don't offer the deep cosmic connection which might be given through the experience of the

night, sea, caves, grass or rain,  
music and dancing to drums,  
fire or  
other adventures.

You may perhaps say out of your experiences just this is not possible for these ill children.

## (4) Horse riding; Die Piraten; Filmproject Mr. ISE Shinichi (Asahi Shimbun March 2007)

But activities from parents in the Cologne 'Parents home' or the project 'Die Piraten' or the film project of Mr. Ise Shinichi about a leisure time - initiated by medical doctors - make sure, how important such '**primeval experiences**' are in those – and of course in all - children lives!

## (5) World-Experience

This means the connection to the physical and social world around us. Every teacher knows the wide range of such connections.

For ill children this experience seems quite limited. The 'world' in the hospital shrinks to a 'small space'. Therefore teachers have to make the world in other ways wide and vivid: 'World' is for ill children everything around them in the hospital:

When the breakfast is given at the bedside it's the chance to connect through it the children to the field of the world by remembering from where the single parts of the meal origins. The classroom should be a field of welcoming the child in the world of learning and culture. There could be organized online teaching and learning too.

(6) **Mobile classroom furniture** might make it easier to link the child at least utterly to the world ‘outside’.

(7) World-Sanctification

‘Sanctification’ is the translation of the German term ‘Heiligung’. *Pfeiffenschneider* speaks here from ‘Weltheiligung’ which is translated with ‘world-sanctification’. It may sound quite pathetic for those who are used to think more secular.

In the expression ‘*world-sanctification*’ are included terms like *whole*, *healing* and *holy*. – These terms can be understood as guidelines for man to experience a ‘*world-unity*’ and help man that he **consciously adapts himself** to this **unification**.

World-sanctification points to **all** educational activities. It helps to re-entry in this primeval unity with the world, followed by the feeling of respect and responsibility.

This knowledge and attitude **on teacher’s side** may help to include the **ill** child in the experience of this wholeness of the world. The world is healing man and has to be healed by man. The world is whole in the meaning of holy and has to be sanctified by our doing.

Meditation, un-conditioned love to the earth, natural rituals, rhythms and the flow of energy in the nature opens the world through our senses.

One point may be specially underlined:

The ‘school performance’ of ill children in the integral-diaphan context cannot be judged (only) by measurable achievements but has to be looked at through individual abilities and genuine personal history.

My study work in Heilpaedagogik and now the topic of this Forum lead me to the epistemological conviction that in the 21<sup>st</sup> century **education** has to be understood **out of an existential core** and has to be realized **on the base of the essence of an integral consciousness**.

(8) In the 21<sup>st</sup> century education has to be understood out of an existential core and has to be realized on the base of the essence of an integral consciousness.

This consciousness is the fundament for developing education in the frame of **Inclusive Education**.

This kind of integral world view and the relevance to educational processes **might be strange** for many – or perhaps all - of us. **We** have been **not** been educated under such a view and with these qualities.

Therefore you may quite legitimately ask the question what has this to do with the “‘real’ reality” of children with cancer and their ‘end-of-life care’?

One answer may be: To go this way demands deep changes of us.

Here is the link to the third part of my presentation.

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**III. ‘Theory – U’ – a way of exploring profound change.**

In my academic work of the last years a research model from the Massachusetts Institute of Technology (MIT) in Boston (USA) influenced my research and teaching. Just a few months ago *Otto Scharmer* published 'Theory U'.

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**Theory U: Universal social grammar for bringing forth new worlds.**

Already the subtitle indicates a proximity to *Jean Gebser's* dimension of **Time**: 'Leading from the **Future** as It Emerges' and the dynamic of a social renewal through what *Scharmer* calls 'The Social Technology of **Presencing**'.

Presencing – a neologism of 'Sensing' and 'Presence'.

When *Jean Gebser* was a thinker who opens us a view on human existence on the base of the archaeology of consciousness, then *C. Otto Scharmer* is an outstanding thinker and scientist too who directs our attention on the **WAY** of 'Exploring profound change in people, organizations and society' as it can be inferred from the subtitle of 'Presencing'. WAY means much more than a 'scientific method' – WAY could be best translated with the Japanese DO.

Before we begin to follow in short steps the 'Process U' it's allowed to ask, why should we take the task and may be the risk to dive in such a dynamic? A possible answer is connected with the planned outcome of the research project. The Japanese research group hopes to develop a practical **model** for **cooperation** of different groups of experts – especially between medical doctors and teachers -and a model for teaching children in the final stage by discussing contents and methods.

Here we can bridge to the situation which *Scharmer* describes, when he speaks about 'a profound blind spot in leadership and in everyday life'. He points that "we can look at leader's work – when I use the word *leader*, I refer to **all people** who engage in creating change or shaping their future, **regardless of their formal positions in institutional structures** – from three different angles. First we could look at *what* leaders do...Second, we could look at the *how*, the processes leaders use...And yet, we have never systematically looked at the leader's work from the third ...perspective. The question we have left unasked is: what **sources** are leaders actually operating from?" This he calls the **blind spot** "...the place within or around us where our attention and intention originates."

I dare to claim, that in science there is no custom to ask 'what **inner sources** are leaders actually operating from'. I also dare to claim, that the fact of 75% of teachers giving up the teaching work before three years has to do with this blind spot. To approach this **inner source** means to extend our learned understanding. It means to rely not only on our 'rational scientific tool.' For *Scharmer* it is obvious: "**Science** needs to be performed with the **mind of wisdom**".

Assuming that groups of experts in and around the hospital school would take the risk to dive into this U, I could imagine the following steps and activities:

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### **RESEARCH.**

***Synthesis between science, social change, and the evolution of self and consciousness.***

From Downloading of patterns of the past in isolated groups →

Initiating an interdisciplinary group →  
Suspending: Seeing with fresh eyes. →  
Deep dive: Sensing from the field →  
Letting go... →  
PRESENCING →  
Letting come... →  
Enacting: Crystallizing vision and action →  
Embodying: Prototyping →  
Institutionalizing

Passing the eye of the needle requires a commitment: “a commitment of letting go everything that isn’t essential and of living according to the ‘letting go/letting come’ principle that *Goethe* described as the **essence of the human journey**.”

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*Johann Wolfgang von Goethe*

‘And if you don’t know this **dying and birth**, you are merely a dreary guest on earth’

Here closes the circle of our thoughts which started with the **existential** situation of children with cancer, their parents and all the other persons around them. We could recognize how today we are confronted with the emergence of an **integral** consciousness which allows us to understand the **ever present origin** and therefore a **paradigmatic new quality of life** – not only for education but for our cultures and the global connectedness. And last but not least we became aware of the need of a **transformation** of ourselves, of organizations and of societies.

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### Conclusion remark

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(1) Children with cancer make clear what life means for them: “One thing I’ll never do: To give up!” and “Only bats let themselves go.”

(2) Are we ready for the commitment to accompany them – and all other children who are educated by teachers or met by experts in different educational fields - by passing **ourselves** – parents, doctors, nurses, social worker, psychologists, educators and others - through the eye of the needle? Are we willing ‘to know this **dying and birth**’?

What I presented might be looked at as hazardous enterprise. I experienced with a group of 20 educational experts from 2005-2007 in Cologne the Process-U. Our project was titled “Teacher-Education-Culture. MOVEMENT PRO INCLUSION”. We got quite unexpected results.

In preparing this congress I personally have become enriched by different new aspects during the last months. At the same time I felt how difficult it is only to *talk about* this topic. Still I feel myself having **not** passed the eye of the needle.

The depth of the phenomena of 'dying and birth' I felt expressed in an essay of Asada Jiro 'Hiroshi's death' which I warmly recommend you to read.

Thank you very much for your attention, your open mind and your open heart!

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**Route U**

I wish all of us the **open will** to start again and again the **scientific, practical and personal journey** on the **Route U** - also together with children with cancer though confronted with them in the final stage of their lives.

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