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## **Part II**

# **CLINICAL PHILOSOPHY OF CARING**

## Chapter 9

# FÜRSORGE IM LEBEN UND STERBEN — AUS PHÄNOMENOLOGISCH-ANTHROPOLOGISCHER SICHT —

### Einleitung

Ich bin, wie es aussieht, dank der Fürsorge anderer geboren, und irgendwann werde ich wahrscheinlich mit der Fürsorge anderer sterben. Zwischen diesen beiden Passivitäten sowohl am Anfang als auch am Ende des Lebens ist es mir doch möglich, mit der Fürsorge anderer für mich selbst wie auch für andere zu sorgen. Obwohl ich eben von „anderen“ gesprochen habe, es ist aber fast unmöglich, im Bereich der Fürsorge ohne Bezug auf konkrete menschliche Beziehungen lediglich abstrakt über die Beziehung des Ichs zu anderen zu diskutieren. Selbst wenn es nicht nötig ist zu fragen, wer, wann, wie, wo für wen sorgt, scheint es mir, dass wir wenigstens zwei Fälle unterscheiden müssen: zum einen, wenn ich für ein „Du“ als intimen, mir nahe stehenden Anderen sorge und im Gegenzug Fürsorge von diesem „Du“ erhalte, zum anderen, wenn ich für ein „Jemand“ als fremden, mir fern stehenden Anderen sorge und im Gegenzug Fürsorge von diesem „Jemand“ erhalte. Während ich im ersten Fall meine Beziehung zum Anderen als „zweite Person“ bezeichnen kann, bezeichne ich im zweiten Fall meine Beziehung zum Anderen als „dritte Person“. In diesem Aufsatz werde ich versuchen, das Problem von „Fürsorge im Leben und Sterben“ aus einer solchen Unterscheidung der personalen Perspektiven phänomenologisch zu betrachten.

## 1. Zur phänomenologischen Anthropologie von Fürsorge

Wenn ich ein bisschen phänomenologische Terminologie benutzen darf, würde ich sagen, „Fürsorge“ ist eine Art von Intentionalität des Bewusstseins, und zwar eine Intentionalität, die mehr in der Dimension des Handelns als in der Dimension des Erkennens funktioniert; überdies eine Intentionalität, die nicht im Selbst eingeschlossen ist, sondern sich auf den Anderen bezieht. Wenn die auf den Anderen gerichtete Intention nicht zur Befriedigung des Anderen führt, wird sie vielleicht zur Befriedigung des Selbst, aber keineswegs zur Fürsorge im eigentlichen Sinne. Zu wenig Fürsorge kann nur zu einem Zuwenig an Freundlichkeit, zu viel Fürsorge nur zu einem Zuviel an Bemühung werden. Weder das eine noch das andere wird zu einer adäquaten Fürsorge. Zwischen „Fürsorge geben“ und „Fürsorge erhalten“ steckt immer die Möglichkeit eines Ungleichgewichts.

Wie oft in Büchern zum Thema „Fürsorge“, wird bei Martin Heidegger in *Sein und Zeit* die fundamentale Seinsweise von Dasein, d.h., wenn ich es einfach sagen darf, von menschlichem Sein, als „Sorge“ bezeichnet, und zwar als „In-der-Welt-Sein“ wie auch als „Mittdasein“. Fürsorge besagt, dass wir Menschen immer schon in der Welt sind in einer Seinsweise, die sich auf den Anderen bezieht. Wenn ich es noch genauer sagen darf, bedeutet Fürsorge, dass ich mich auf den Anderen beziehe und gleichzeitig der Andere sich auf mich bezieht, d.h. dass ich mit dem Anderen in der Beziehung „Fürsorge geben und Fürsorge erhalten“ lebe. In husserlscher Terminologie ausgedrückt, ist dieses Verhältnis eine „intersubjektive Seinsweise in unserer Lebenswelt“, oder in der Terminologie von Bernhard Waldenfels oder Bin Kimura: das Phänomen des „Zwischen“, das Menschen verbindet.

Es handelt sich dabei jedoch nicht um eine homogenisierte Gemeinsamkeit im „Wir“. Die phänomenologisch verstandene intersubjektive Welt ist eine perspektivische Welt mit einer sich vom Ausgangspunkt des „Jetzt-Hier-Ich“ strahlenförmig ausbreitenden Aussicht auf eine nicht-homogene Welt, welche sich durch den Wechsel des Standpunkts und der Kommunikation zwischen diesem „Ich“ und dem „Anderen“ mit einer jeweils anderen Perspektive konstituiert. Das Wort „Perspektive“, das normalerweise im räumlichen Zusammenhang verwendet wird, verwendet Husserl auch im zeitlichen Sinne, doch wir können den Begriff noch weiter ausdehnen und auch im personalen Sinne verwenden. Die perspektivisch betrachtete Welt ist also

eine Welt, die *räumlich* Oben-Unten, Links-Rechts, Vorne-Hinten, Ferne-Nähe, *zeitlich* Vergangenheit-Gegenwart-Zukunft, Ferne-Nähe sowie *personal* die Verschiedenheit der Beziehungen von erster, zweiter und dritter Person enthält.

Um das Thema „Fürsorge im Leben und Sterben“ phänomenologisch zu betrachten, müssen wir die Seinsweise der menschlichen Beziehung als auch die Personalität der Beziehung in Betracht ziehen. Sowohl wenn ich geboren werde, als auch wenn ich sterbe, sind wir in eine solche Seinsweise der Beziehung und ihrer Personalität eingebunden. Sowohl die Geburt als auch der Tod — wenn ich buddhistisch sprechen darf „Geburt, Alter, Krankheit und Tod“ (Shiku: 四苦) — sind ein Ereignis im „Zwischen“-Modus einer Beziehung mit personaler Verschiedenheit. Wenn Arthur Kleinman in *The Illness Narratives* zwischen „disease“ als Gegenstand der objektiven Medizin und „illness“ als gelebtes, subjektives Erlebnis unterscheidet, können wir darin genau diese Unterscheidung zwischen der in der dritten Person erfassten Krankheit und der in der ersten Person gelebten Krankheit erkennen. Und was den „Tod“ betrifft: Wenn Vladimir Jankélévitch in *La mort* zwischen dem Tod in der ersten, der zweiten und der dritten Person unterscheidet, können wir darin untergründig eine phänomenologische Sichtweise erkennen. Und auch bezüglich des buddhistischen „Leidens“ von „Geburt, Alter, Krankheit und Tod“ können wir die leidende Person als erste Person, die sie mit „Du“ anredende Person als zweite Person und die andere, für die beiden sorgende Person als dritte Person bezeichnen.

Entsprechend ist die medizinische Betreuung auch die Welt, wo sich die personale Verschiedenheit zeigt. Vor allem in der Sterbemedizin (terminal care) wird diese Verschiedenheit deutlich. Die Verschiedenheit der Person wirft auch die Frage auf, wer der Betroffene ist. In der medizinischen Betreuung am Lebensende ist es der im Angesicht des Todes leidende Patient in der ersten Person. Wenn Krankheit und Tod ein Ereignis im Modus des „Zwischen“ ist, können wir auch die Familie oder Freunde und Freundinnen des Leidenden, die mit ihm in der Beziehung des „Du“ stehen, als Betroffene bezeichnen. Und weiter können wir auch die Beteiligten, die sich mit der Sterbemedizin beschäftigen, als das Ereignis mittragende Betroffene bezeichnen, auch wenn nur im Sinne einer Beziehung der dritten Person. (Folglich bedeutet dies: Wenn „Euthanasie“ als Verbrechen geahndet wird, werden die medizinisch Verantwortlichen zu Betroffenen des Verbrechens.)

Weil eine solche Verschiedenheit der Person und der Perspektive auch in der

medizinischen Behandlung eine große Rolle spielt, ist es auch da nötig, die Verschiedenheit der Person und der Perspektive durch Kommunikation auszubalancieren. In Wirklichkeit gelingt die Kommunikation nicht immer gut; es kann geschehen, dass die Standpunkte verschieden und die Meinungen geteilt sind. Dabei ist es wichtig, dass die Verschiedenheit der Person aus der phänomenologischen Beziehung der „Fundierung“ eine vorrangige Ordnung hat. Wen wir also für primär wichtig halten müssen, ist der leidende und sterbende Patient selbst in der ersten Person. Sekundär wichtig ist die Person, die in der „Du“-Beziehung mit dem Patient steht, und diejenigen, die den sterbenden Patient medizinisch begleiten und betreuen. Damit wir eine solche Vorrangsordnung nicht aus den Augen verlieren, müssen wir bei der Kommunikation die verschiedenen Standpunkte (Perspektiven) gegenseitig achten und beachten.

Eine solche Betrachtung koinzidiert mit Problemen der Bioethik. In der Bioethik diskutiert man, einerseits, über das mit dem Gesetz zusammenhängende Problem von Recht, Pflicht und Gerechtigkeit, andererseits auch über Fragen der Fürsorge wie z.B. über die „Quality of Life“ (QOL) oder das „Cure and Care“ (CAC) von Patienten. Die Diskussion in der Ethik, ob als deren Fundament die Gerechtigkeit (justice), das Recht (law) oder die Fürsorge (care), Verantwortlichkeit (responsibility) gelten sollte, wird auch in der Bioethik geführt. So werde ich im nächsten Paragraph — aus der Perspektive der phänomenologischen Anthropologie — einen Blick auf die Unterschiede zwischen der „Ethik der Gerechtigkeit“ und der „Ethik der Fürsorge“ werfen.

## **2. Eine andere Lesart von *In einer anderen Stimme***

Die Debatte „Gerechtigkeit vs. Fürsorge“, die durch die Veröffentlichung von Carol Gilligans Buch *In einer anderen Stimme* ausgelöst wurde, ist vorwiegend als Feminismus-Debatte geführt worden, weil Gilligan selbst den Gegensatz zwischen der „Ethik der Gerechtigkeit“ und der „Ethik der Fürsorge“ an mehreren Stellen als Gegensatz zwischen „Männer-Gerechtigkeit“ und „Frauen-Fürsorge“ bezeichnet. Aber hier möchte ich nicht auf diese Interpretationsweise eingehen, sondern den Gegensatz anders verstehen.

Wenn Gilligan in der „Einleitung“ schreibt: „Es gibt zwei Weisen, über Moral zu sprechen und über die Beziehung zwischen dem Anderen und dem Ich etwas zu sagen“, d.h. dass es „eine andere Stimme“ gibt, dann lenkt sie die Aufmerksamkeit darauf, dass es sich bei der „anderen Stimme“ nicht um die „andere Stimme“ des anderen Geschlechts (gender) handelt, sondern um eine Verschiedenheit des Themas. Sie will nämlich die Verschiedenheit von Moral bzw. Ethik nicht aus der Verschiedenheit des Geschlechts herleiten, sondern aus der Verschiedenheit, die davon herrührt, dass man in Bezug auf das Verhältnis vom Selbst und dem Anderen die „Individuation“ oder auch die „Abhängigkeit“ anders erfährt. Während sie das schreibt, bedient sie sich trotzdem wiederholt des Kontrastes Männer — Frauen und ruft so Missverständnisse hervor.

Wenn ich aber Gilligans Warnung in der „Einleitung“ wirklich ernst nehme und den Kontrast zwischen „Ethik der Gerechtigkeit“ und „Ethik der Fürsorge“, den sie beschreiben wollte, mit der Beseitigung der geschlechtlichen Verschiedenheit mir noch einmal vor Augen führe, komme ich zu folgendem Gedanken: Während die „Ethik der Gerechtigkeit“ der „Ethik des Rechts“ entspricht, entspricht die „Ethik der Fürsorge“ der „Ethik der Verantwortlichkeit“. Der ersten Ethik zufolge besteht die Welt „aus selbständigen Menschen“ bzw. „aus einem System von Gesetzen“, während sie der zweiten Ethik zufolge eine Welt aus „menschlichen Verhältnissen“ bzw. „menschlichen Verbindungen“ ist. In beiden Fällen ist die „Vorstellung vom Selbst und vom menschlichen Verhältnis“ verschieden — je nachdem, was vorrangig ist: die Trennung von den Anderen oder die Verbindung mit den Anderen.

Anders gesagt, die „Ethik der Gerechtigkeit“, in der jedes einzelne, selbständige Individuum Rechte und Pflichten hat, basiert auf der Vorstellung, dass jedes Individuum gleich behandelt werden soll, während die „Ethik der Fürsorge“ auf einer Vorstellung basiert, dass Menschen in Beziehungen zueinander stehen und auf einander angewiesen sind, sowie auf einer Verantwortlichkeit, mit der jemand auf den Ruf eines Anderen reagiert. Während die „Ethik des Rechts“ auf Gleichheit beruht und sich mit der Auffassung von Gerechtigkeit beschäftigt, gründet die „Ethik der Verantwortlichkeit“ auf der Erkenntnis, dass jeder seine je eigenen Bedürfnisse und Ansprüche hat. Die „Ethik der Fürsorge“ legt den Schwerpunkt auf die Sympathie und die Verantwortlichkeit für das konkrete Gegenüber. Ihr liegt die Erkenntnis zugrunde, dass die Menschen im Verhältnis des Voneinander-abhängig-Seins

(interdependency) leben. Im Gegensatz dazu legt die „Ethik der Gerechtigkeit“, die die Menschen in ihrer Gesamtheit betrachtet, sie also, um es mit den Worten Merleau-Pontys zu sagen, überfliegend überschaut („pensée de survol“), den Schwerpunkt auf die Gerechtigkeit, damit jedem die gleiche Gunst und der gleiche Anteil von etwas zukommt. Weil bei der Gerechtigkeit die Gefahr besteht, angesichts des konkreten, leiblich anwesenden Gegenübers die Gleichheit aus den Augen zu verlieren, trägt „die Göttin der Gerechtigkeit eine Augendecke“. Vom Gesichtspunkt der Personalität aus gesehen, kann man sagen, dass die „Ethik der Fürsorge“ die Beziehung ins Zentrum rückt, in der sich die erste und die zweite Person von Angesicht zu Angesicht gegenüber stehen, während die „Ethik der Gerechtigkeit“ das Schwergewicht auf die dritte Person legt, d.h. auf eine abstrakte Gleichheit der Menschen, die sich nicht konkret begegnen müssen.

An dieser Stelle möchte ich noch kurz auf ein Merkmal hinweisen, das beide Ethiken kontrastiert. Gilligan zufolge ist die „Ethik der Gerechtigkeit“ eine „formale und abstrakte Denkweise“, welche „das moralische Dilemma für eine Art mathematisches Problem hält, daraus eine Gleichung bildet und eine Lösung zu suchen anfängt“. Die „Ethik der Fürsorge“ ist hingegen „eine kontextuelle und narrative Denkweise, welche „in dem Dilemma nicht ein mathematisches Problem, sondern eine Erzählung der menschlichen, sich über die Zeit ausbreitenden Beziehung sieht. Hier wird der Kontrast beider Ethiken als Kontrast zwischen dem vom Kontext absehenden, abstrahierenden Denken und dem den Kontext einbeziehenden, narrativen Denken verstanden. Es lohnt sich, diese Diskussion im Zusammenhang mit der neueren Narrativ-Theorie zu prüfen, es bleibt jedoch hier kein Platz dafür.

Nun, nachdem wir den Kontrast beider Ethiken als einen Kontrast in der Beziehung zwischen dem Ich und dem Anderen begriffen haben, möchte ich noch hinzufügen, dass Gilligan beide Ethiken nicht einfach dualistisch gegenüberstellt, sondern sagt, dass beide „sich ergänzend zur Reife kommen“. Das liest sich, als könnte der aus der Verschiedenheit der Personen rührende Unterschied aufgehoben werden, aber ich denke, dass diese Frage der weiteren Erläuterung bedarf. Im nächsten Abschnitt möchte ich deswegen das Problem der Personalität vertiefen und meinen Blick auf die Diskussion werfen, die, sich auf Gilligans Kontrastierung berufend, im Bereich der Bioethik (bioethics) und der Medizinethik (ethics of medicine) für eine Sonderstellung der Pflegeethik (ethics of nursing) eintritt.

### 3. Vorzüge und Mängel einer Ethik „der 2.5ten Person“

Bisher wurde die Bioethik (oder die Medizinethik) meistens im Rahmen des Verhältnisses zwischen Arzt und Patient oder zwischen Arzt und Gesetz diskutiert. Da gab es kein Platz für die Pflegepersonen. Aus dieser Situation heraus gab es nun einige Versuche, Pflegeethik nicht einfach als Teil der Bioethik betrachten, sondern sie deutlich von der auf die Ärzte fixierten Medizinethik abzuheben und als eigenständige Pflegeethik zu denken. Ein Auslöser war auch Gilligans Gedanke, auf den ich im letzten Abschnitt hingewiesen habe.

Ein Versuch, Pflegeethik als etwas Eigenständiges zu begreifen, ist Daniel F. Chambliss' Buch *Jenseits der Pflege (Beyond caring: Hospitals, nurses, and the social organization of ethics)*. Was für ein Wesen ein Pfleger ist, was für eine Handlung seine Pflege ist, das charakterisiert er, im Unterschied zu dem, was ein Arzt tut, folgendermaßen: Erstens geschieht Pflege unmittelbar, von Angesicht zu Angesicht, in fortwährender gegenseitiger Vergewisserung. Zweitens wird bei der Pflege der Patient nicht bloss als ein biologisch-medizinisches Objekt bzw. als ein von einer Krankheit befallener Körper betrachtet. Drittens ist die Arbeit der Pflege endlos. Viertens ist Pflege ohne tiefen, zwischenmenschlichen Beziehung nicht möglich. Und nicht zuletzt sind Pflegepersonen professionell ausgebildet. Trotz all dem nimmt das Pflegepersonal innerhalb der Krankenhaushierarchie eine weit niedrigere Stellung ein als Ärzte und wird, was Macht und Ansehen betrifft, fundamental benachteiligt. Von daher kommt, folgert Chambliss, das „Dilemma der Pflegerolle“ und das Problem der Pflegeethik ganz allgemein. Es gebe „einen strukturellen Streit der Weltanschauungen“ zwischen Pflegepersonal und Ärzten.

In diese Kontroverse eingreifend, fordert Helga Kuhse in ihrem Buch *Pflegen (Caring: Nurses, Women and Ethics)*, dass der Schwerpunkt auf die Stellung des Pflegers gelegt werden müsse. Wie Chambliss, die vor allem auf die Konflikte zwischen Pflegepersonal und Ärzten in der Sterbemedizin hingewiesen hat, nimmt auch Kuhse dieses Problem auf und stellt die Frage, warum nur ein Arzt Wiederbelebungsmaßnahmen stoppen kann (DNR: do not resuscitate), warum nur ein Arzt darüber entscheiden kann, wie viel palliative Betreuung für einen sterbenden Patienten nötig ist, warum nicht eine Pflegeperson. Sie meint, ob nicht „gerade die Pflegeperson eine solche Entscheidung treffen sollte“. Sich auf die Debatte

„Gerechtigkeit contra Fürsorge“ berufend, sagt sie, dass „Gerechtigkeit und Pflege einen ethischen Rahmen bilden“, und fordert radikal, dass der Pflegeperson das Recht zukommen sollte, für Patienten im Endstadium eine bestimmte palliative Behandlung anzurufen oder sich gar im Einvernehmen mit dem urteilsfähigen, sterbenden Patienten für das Stoppen der lebenserhaltenden Maßnahmen zu entscheiden.

Kurz gesagt, beinhaltet dies zwei Forderungen: Einmal, dass statt des bisherigen „Diktat des Lebens“ die Interessen des Patienten sowie die Achtung des Rechts zur Selbstbestimmung zum Prinzip der Medizin werden sollte, was auch die gesetzliche Regelung der eigenverantwortlichen Euthanasie beinhaltet. Und zum anderen, dass in der Sterbemedizin das Pflegepersonal die Verantwortung für den Behandlungsplan übernehmen sollte.

Sich stets auf Gilligan beziehend, zielt Kuhse darauf ab, „Fürsorge“ und „Gerechtigkeit“ zu vereinen. Für eine geeignete Ethik sei neben der Fürsorge auch Gleichheit und Gerechtigkeit notwendig, sagt sie und behauptet außerdem, dass es bei der Gegenüberstellung von „Fürsorge“ und „Gerechtigkeit“ nicht um das Problem des Geschlechts (gender) gehe. Denn eine Entsprechung zwischen Geschlecht und Moral sei rein zufällig und auch die Möglichkeit mit sozialen und historischen Gründen sei zu denken. So verlässt sie die Frage nach dem Geschlecht und versucht die im Geschlechtlichen gefangene Debatte „Gerechtigkeit contra Fürsorge“ als Konflikt zwischen der „auf dem Prinzip der Gleichheit beruhenden Ethik der Gerechtigkeit“ und der „nicht auf dem Prinzip der Gleichheit beruhenden Ethik der Fürsorge“ umzudeuten. In dem Sinn, nicht aus einer Gender-Perspektive gelesen, stimmt sie mit meiner oben genannten Lesart überein, obwohl der gedankliche Hintergrund völlig verschieden ist. Doch Kuhse denkt in eine ganz andere, gegenteilige Richtung weiter. Sie sagt: „Wenn der Ansatz dahin geht, die Autonomie des Individuums hochzuschätzen, die Interessen des Patienten zu wahren und den Wunsch nach Selbstbestimmung ernst zu nehmen, bedeutet das auch, nicht nur das Individuum als autonom entscheidendes Wesen hochzuschätzen, sondern das Individuum auch als ein durch menschliche Beziehungen sich definierendes Wesen zu sehen und dem Rechnung zu tragen“. An diesem Punkt behauptet sie: „Der Ansatz, den ich vorgezeichnet habe, erfüllt beide Forderungen, sowohl jene der Gerechtigkeit als auch jene der Fürsorge, und kann meiner Meinung nach zwischen beiden eine Brücke schlagen“.

Kuhses Versuch der Umwandlung der Metapher von der Pflegeperson als ein „dem Arzt untertäniges Dienstmädchen“ zu einem „Stellvertreter des Patienten“ bedeutet, nicht nur das Verhältnis zwischen Pflegeperson und Arzt, sondern auch das Verhältnis zwischen Pflegeperson und Patient zu verändern. Wenn sie verlangt, „dass die Fürsorge der Pflegeperson dem Patienten die Selbstbestimmung ermöglichen und auch im Endstadium Gerechtigkeit und Gleichheit gewährleisten muss“, kann ich das noch akzeptieren. Wenn sie jedoch fordert: „Wenigstens bei der Fürsorge im Endstadium soll das Recht zu den letzten Entscheidungen beim Krankenpfleger liegen“, konkret ausgedrückt: „Die zuständige Pflegeperson soll eine DNR-Anweisung geben können und zudem für den Bedarf oder Nichtbedarf einer palliativen Behandlung, für Maßnahmen zur Lebensverlängerung oder Lebensbeendung, d.h. für spontane Euthanasie und Sterbehilfe verantwortlich sein“ — wenn sie das fordert, dann muss ich sagen: Das geht zu weit.

Oben habe ich zwischen dem Patient als erster Person, seinem Familien- und Freundeskreis als zweiter Person sowie der medizinisch Beteiligten als dritter Person unterschieden. Obwohl ein Arzt zur dritten Person gehört, wäre eine Pflegeperson sozusagen als „die 2.5te Person“ zu bezeichnen, weil sie dem Patienten und seinem Familien- und Freundeskreis noch näher steht. Daraus, dass eine Pflegeperson ihrem Patienten näher steht als der Arzt, schließt Kuhse, dass sie in der Lage ist, durch die fürsorgebedingte Nähe zum Patienten auch für Gerechtigkeit zu sorgen. Aber in ihrem Gedanken fehlt der Aspekt des Familien- und Freundeskreises ganz und gar. Durch ihre Art, Arzt und Pflegeperson miteinander zu konfrontieren und den Standpunkt der Pflegeperson zu verteidigen, geht der Aspekt der zweiten Person völlig unter. Oder hat diese Beurteilung in Wirklichkeit mehr mit meiner japanischen Denkart zu tun?

An dieser Stelle möchte ich auf Gilligans Buch *In einer anderen Stimme* zurückblicken und schauen, was sie im „Nachwort zur japanischen Übersetzung“ hinzugefügt hat. Darin heißt es: „Das in diesem Buch aufgeworfene Problem wird noch interessanter und eröffnet eine neue Perspektive, wenn man den kulturellen Unterschied bezüglich moralischer Anschauung in Betracht zieht.“ Sie schreibt: „Der Gedanke, den Hauptwert auf das Recht des Individuums zu legen, gehört zum Kern der amerikanischen Tradition, während die japanische Gesellschaft das Voneinander-abhängig-Sein (interdependency) hochschätzt und sich auch im Rahmen dieser

Abhängigkeiten (amae - 甘え) bewegt.“ Sie sieht also die „Ethik der Gerechtigkeit“ in der amerikanischen Tradition und die „Ethik der Fürsorge“ in der japanischen Tradition. Hier haben wir m. E. einen Anhaltspunkt, um das Problem der zweiten Person, d.h. des Familien- und Freundeskreises, durch den Blick auf den kulturellen Unterschied zu revidieren. Als nächstes möchte ich mich also der Diskussion über die aktuelle Sterbemedizin in Japan zuwenden.

#### **4. Sterbemedizin in Japan**

Im März des letzten Jahres ist von dem Zwischenfall zwei Monate lang fast täglich berichtet worden: dass im städtischen Krankenhaus von Imizu (Präfektur Toyama) die künstliche Beatmung von sieben an Krebs und anderen unheilbaren Krankheiten leidenden Patienten abgestellt wurde. In den Berichten tauchten viele interessante Informationen auf, von denen ich hier drei nennen möchte. Erstens: Was den Willen des Patienten und das Einverständnis seiner Familie betrifft, scheint es eine „stillschweigende Zustimmung“ zum Entscheid des Arztes geben zu haben, die schriftlich nicht festgehalten war. Zweitens: Die Entscheidung ist von anderen Mitgliedern des medizinischen Personals nicht überprüft worden. Der zuständige Chefarzt hat also mit hoher Wahrscheinlichkeit die Entscheidung allein getroffen. Drittens: Auf Grund dieser Vorkommnisse werden von den Krankenhäusern und/oder vom Staat klare Verhaltensregeln gefordert.

Über die Transplantation von Organen hirntoter Menschen wurde 1997 in Japan mit Mühe und Not ein Gesetz eingeführt („Gesetz über die Organtransplantation“). In diesem Zusammenhang sind auch die „Gesetzliche Ausführungsbestimmung“, der „Leitfaden zur Anwendung“ und das „Manual zur gesetzlichen Bestimmung des Hirntodes“ entstanden. Obwohl im Einzelnen noch manche Probleme ungeklärt sind, wurden auf Grund dieser neuen Regel bis Ende letzten Jahres (2006) 50 Organtransplantationen nach dem Hirntode durchgeführt. Im Parlament sind neulich zwei Revisionsentwürfe vorbereitet worden, mit denen nicht nur der Revisionsbedarf des Gesetzes über die Organtransplantation, sondern auch die Notwendigkeit von Verbesserungen bezüglich Ausführungsbestimmungen, Leitfaden und Spenderkarte (donor card) deutlich wurde, worauf ich hier im Einzelnen nicht eingehen kann. Trotz

vieler Schwächen schätze ich doch die Grundidee dieses Gesetzes, dass nur bei Erfüllung folgender zwei Bedingungen: „Schriftliche Willensäußerung des Patienten“ und der „Zustimmung seiner Familie“ sowie bei Erfüllung der gesetzlichen Bestimmung des Hirntodes eine Organentnahme möglich ist. Die „Bestimmung des Hirntodes“ (dritte Person) nach dem „Willen des Patienten“ (erste Person) und die „Zustimmung der Familie“ (zweite Person) ist also ein Ergebnis, die der in der japanischen Kultur verwurzelten Medizin entspricht. Das ist m.E. als Grundidee nicht schlecht.

Leider gibt es keine entsprechende Regel für die japanische Sterbemedizin. Ein Teil des Strafgesetzes befasst sich zwar mit der Beihilfe zum Selbstmord, die als Mord taxiert wird, darüber hinaus sind aber nur die „drei Bedingungen für das Beenden lebensverlängernder Maßnahmen (Sterben mit Würde)“ und die „vier Bedingungen für die Euthanasie“ einigermaßen verbindlich, welche beim Urteilsspruch vom vergangenen Zwischenfall (in der Universitätsklinik der Tokai-Universität, 1995) angewandt wurden und einen Präzedenzfall bildeten. Ich bin jedoch nicht der Meinung, dass ein Gesetz in der Art eingeführt werden soll, wie die ehemalige (japanische) Gesellschaft für Euthanasie dachte, oder wie Euthanasie-Gesetz in den Niederlanden und in Belgien, oder wie das Gesetz für würdevolles Sterben (Beihilfe zum Selbstmord) in Oregon in den USA. Weil es sich in Japan anders verhält als in Ländern, in denen das individualistische Denken und das System des Hausarztes tief verankert sind, sollte man, wie im Fall der Organentnahme bei Hirntod, für die Sterbemedizin ein Gesetz erwägen, bei dem grundlegende Werte und Anschauungen der japanischen Kultur ebenso wie spezifische Eigenheiten des medizinischen Systems in Betracht gezogen werden.

Dann müsste man sich fragen, wie weit sich die beiden japanischen Bedingungen von der „Willensäußerung des Patienten“ und der „Zustimmung seiner Familie“ für eine Organentnahme bei Hirntod auch für die Sterbemedizin anwenden lassen. Entsprechend der sogenannten Spenderkarte (donor card), die das Einverständnis zur Organentnahme schriftlich bezeugt, so verbreit die „Vereinigung für würdevolles Sterben“ (sie soll mehr als 110,000 Mitglieder haben) ihr „Manifest für würdevolles Sterben (living will)“. Weil dieses Manifest aber in allen drei darin aufgeführten Punkten problematisch ist (darauf kann ich hier im Detail nicht eingehen), weder eine Unterschrift der Familie noch eine Bestätigung des Arztes enthält und gesetzlich

in keiner Weise verbindlich ist, kann auch ein Arzt, der den darin ausgedrückten Willen achten möchte, diesem Willen nur schwer folgen. Dann finde ich die „Patientenverfügung (let me decide)“ für empfehlenswerter, die inhaltlich genauer gefasst ist und von zwei Vertretern (das können Familienmitglieder sein) sowie von einem Hausarzt unterschreiben sein müssen. Darin gibt es auch ausführliche Auswahlmöglichkeiten von Behandlungsmethoden und Platz für eine freie Beschreibung persönlicher Wünsche. Obwohl auch bei der Patientenverfügung noch Fragen offen bleiben, wäre es m. E. besser, wenn ein solches Dokument gesetzliche Verbindlichkeit haben würde.

Das ist die Situation, in der im September vergangenen Jahres das japanische Ministerium für Gesundheit, Arbeit und Wohlfahrt den „Leidfaden zur Sterbemedizin (Vorschlag)“ zusammengestellt, im Internet veröffentlicht und um die öffentliche Meinung gebeten hat. Die Vorschläge lauten im Wesentlichen: 1. Auf der Basis von medizinischer Angemessenheit und dem Willen des Patienten sollten Ärzte und Pflegepersonal mit Hilfe von Fachleuten aus unterschiedlichen Gebieten eine vorsichtige Entscheidung treffen. 2. Schmerzen und andere unangenehme Symptome sollten so weit wie möglich gemildert werden. Ferner soll der Patient eine ganzheitliche Behandlung bekommen, die auch seelische und soziale Unterstützung beinhaltet. 3. Eine auf aktive Euthanasie bzw. Beihilfe zum Selbstmord abzielende Behandlung soll als medizinische Lösung keinesfalls anerkannt werden. Darüber hinaus sollte man in der Sterbemedizin prinzipiell zwei Fälle unterscheiden: Erstens der Fall, wo der Wille des Patienten bekannt ist, zweitens der Fall, wo er nicht bekannt ist. Im ersten Fall sollte die Willensentscheidung des Patienten mit der Einverständniserklärung (informed consent) als Basis genommen werden und der Patient im Gespräch mit dem medizinischen Team seinen Willen noch einmal deutlich machen — um sicher zu gehen, dass er seine Meinung nicht geändert hat oder ändern möchte. Im zweiten Fall sollte man versuchen, den Willen des Patienten durch das Gespräch mit den Angehörigen herauszufinden. Falls das auch schwierig ist, sollte auf Grund der Gedanken und Ratschläge der Familie die für den Patienten beste Lösung gefunden werden. Wenn Patient und medizinisches Team zu keinem gegenseitigen Einverständnis gelangen oder wenn die Meinungen im Team gespalten sind, sollte im Krankenhaus ein Ausschuss von unterschiedlichen Fachleuten gebildet werden, der dann die definitiven Entscheidungen fällt.

Obwohl ich hier nicht ausführlich darauf eingehen kann, hege ich einige Befürchtungen: Obwohl die Familie im ersten Fall in die seelische und soziale Hilfe eingebunden wird, ist es ihr nicht erlaubt, am Gespräch zwischen dem Patient und dem medizinischen Team teilzunehmen. Dadurch wird zwar gewährleistet, dass die Familie keinen Druck auf die Meinung des Patienten ausüben kann, aber fraglich ist es trotzdem, ob es sinnvoll ist, wenn Patient und medizinisches Team unter völligem Ausschluss der Familie einen Entscheid fällen. Im zweiten Fall wiederum kann man sich fragen, ob es sinnvoll ist, den Willen des Patienten aus dem Gespräch mit seinen Angehörigen abzuleiten, wenn das Verhältnis zwischen dem Patienten und seiner Familie nicht gut ist. Gerade als man über diesen „Leitfaden“ diskutierte, wurde im Dezember letzten Jahres (2006) die japanische Übersetzung des *Zwischenberichts der Enquête-Kommission „Ethik und Recht der modernen Medizin“* über Patientenverfügungen (2004) veröffentlicht. Darin wurden die Unterschiede zwischen den Verhältnissen in Japan und Deutschland deutlich sichtbar.

## 5. Die Patientenverfügung im kulturellen Vergleich

Der Bericht des Bundestages betrachtet den „Zusammenbruch der traditionalen Familie“ als status quo der Gegenwart. Vor dem Hintergrund dieser tiefgreifenden „Veränderung der Gesellschaft“ wird darin behauptet: „Eine Patientenverfügung ist sinnvoll, solange man damit die Dinge schriftlich festhalten kann, in denen früher allgemeine Meinungen zur Übereinstimmung kommen konnten oder über die in der Familie miteinander gesprochen wurde.“ Aus diesem Grund schlägt er auch einen konkreten Entwurf vor, um die Patientenverfügung gesetzlich zu regeln.

Im Vergleich mit dem oben genannten japanischen „Leitfaden“ fällt auf, dass der deutsche Bericht nicht nur konkret die Patientenverfügung regelt, sondern grundsätzlich über das Problem nachdenkt und in einen umfassenden Kontext zu stellen versucht, was mir für Deutschland typisch scheint. In der „Zusammenfassung“ heißt es: „Entscheidend ist vielmehr eine verbesserte Begleitung schwerkranker und sterbender Menschen sowie die Stärkung von Palliativmedizin und Hospizeinrichtungen. Die Debatte um Patientenverfügungen muss stets in diesen Kontext eingebettet werden.“ Auch in der Einleitung steht, „dass die Fragen zum

Thema Patientenverfügungen im Gesamtkonzept der Sterbebegleitung und Palliativmedizin gesehen werden müssen.“ Zum Kontext äußert sich der Zwischenbericht, ihn zu umreißen versuchend: „Die viel weiter gehenden Fragen der Sterbebegleitung, die die Befriedigung körperlicher, psychischer, sozialer und spiritueller Bedürfnisse umfasst, werden von vielen Patientenverfügungen nicht erfasst, bestimmen aber gleichwohl wesentlich die Debatte um den Stellenwert der Patientenverfügung und den Umgang mit ihr.“ Die Selbstbestimmung des Patienten qua Patientenverfügung sollte also innerhalb dieses Kontextes diskutiert werden.

Der Bericht stellt einerseits fest, „dass das Recht auf Selbstbestimmung ein fundamentales Menschenrecht ist“, vergisst aber andererseits nicht hinzufügen, dass es nicht isoliert betrachtet werden sollte. Die Patientenverfügung sollte deswegen „in den Gesamtzusammenhang von individueller Freiheit, menschlichem Wohl, ärztlichen und pflegerischen Pflichten, patientenrechtebasierter Regeln und medizinischer Effektivität gestellt“ werden. Darin offenbart sich eine andere Einstellung als die der liberalistischen Bioethik (bioethics) im angelsächsischen Bereich, die den Willen des Individuums über alles stellt, solange es anderen nicht schadet.

Das erinnert mich daran, dass der vorangehende Bericht, d.h. der *Schlussbericht der Enquete-Kommission „Recht und Ethik der modernen Medizin“* des Deutschen Bundestages aus dem Jahr 2002 (in japanischer Übersetzung unter dem Titel *Menschenwürde und Genetische Daten* erschienen), mit der „Menschenwürde“, der Grundvoraussetzung im ersten Kapitel des deutschen Grundgesetzes, beginnt und beim historischen Rückblick den Menschen als „freies und abhängiges Wesen“ betrachtet. Dieser Bericht hält fest, „dass Menschen immer auch leibliche, unvollkommene und verletzbare Wesen sind, und wir müssen die Achtung gerade derjenigen sicherstellen, die auf Schutz besonders angewiesen sind [...] Der Mensch muss daher keine besonderen Eigenschaften oder Fähigkeiten besitzen, um vom Schutzanspruch der Menschenwürdegarantie erfasst zu sein. Ob alt oder jung, stark oder schwach, krank oder gesund — jeder Mensch hat Anspruch auf Achtung seiner Würde. [...] Jeder Mensch ist zumindest in vielen Phasen seines Lebens (z. B. Kindheit, Krankheit, Alter) für die Wahrnehmung seiner individuellen Freiheitsrechte von der Unterstützung durch andere abhängig.“ Hier richtet man den Blick nicht nur auf den Menschen als selbständiges, freies und ein Recht auf Selbstbestimmung habendes Wesen, sondern auch auf den Menschen als schwaches, verletzliches und

unvollkommenes, abhängiges Wesen, das auf die Hilfe anderer angewiesen ist. Beim Problem der Patientenverfügung muss diese Ambivalenz in der Natur des Menschen in Betracht gezogen werden. Soweit die deutsche Sichtweise.

Nun möchte ich noch einmal den Blick auf die gegenwärtige Situation in Japan werfen und den Bericht von der jüngsten Debatte „Noch einmal Sterbemedizin“ (2006) des japanischen Ärzteverbandes erwähnen, der im Februar letzten Jahres veröffentlicht wurde. Darin fällt auf, dass in der Sterbemedizin nicht nur allein der Wille des Patienten geachtet werden, sondern im Gespräch auch die Familie zum Einverständnis kommen soll. Im Bericht heißt es: „In der Sterbemedizin, vor allem am Scheidweg zwischen Leben und Tod oder auch bei der Entscheidung darüber, wie die Behandlung am besten durchgeführt werden soll (z.B. zu Hause oder in einer Pflegeeinrichtung), gibt es Fälle, wo die Entscheidung nicht nur ein Problem für den Patienten, sondern auch für die ihn unterstützenden, ihm beistehenden Familienangehörigen ist. In einem solchen Fall ist nicht die alleinige Entscheidung des Patienten, sondern vielmehr eine gemeinsame Entscheidung wünschenswert, entstanden durch das einführende Gespräch mit der Familie.“

In diesem Bericht wird auch auf einige Problempunkte in Zusammenhang mit der Patientenverfügung hingewiesen, z. B.:

- Die Einschätzung des Patienten ist nicht immer zutreffend.
- Vom Zeitpunkt der Erstellung der Patientenverfügung bis zum Zeitpunkt ihrer Anwendung könnte der Wille des Patienten sich geändert haben.
- Auch die Art und Weise, wie die Patientenverfügung erworben wird, ist zu überdenken.
- Was Prognosen am nahenden Lebensende betrifft, sind Meinungsverschiedenheiten in Bezug auf die „Unmöglichkeit einer Besserung“ oder die „verbleibende Lebenszeit“ nicht zu vermeiden.

Hier zeigt sich die Notwendigkeit, sorgfältig zu überprüfen, ob die Patientenverfügung medizinisch wirklich angemessen ist oder nicht.

Um auf das Problem der Familie zurückzukommen: Wie erwähnt geht der deutsche Bericht vom „Zusammenbruch der traditionalen Familie“ aus. Obwohl Ausdrücke wie „Familie“ oder „Verwandtschaft“ darin vorkommen, haben sie kaum Gewicht; viel häufiger werden Begriffe wie „Vertreter“, „Betreuer“, „Bevollmächtigter“ und dergleichen benutzt. Dieser Bericht offenbart eine andere Einstellung als die

angelsächsische Bioethik, in der das Recht auf Selbstbestimmung sozusagen absolut gesetzt wird. Der Unterschied liegt vor allem darin, dass der deutsche Bericht die grundsätzliche Abhängigkeit der Menschen voneinander betont — obwohl er diese Abhängigkeit nicht mehr auf die traditionale Familie bezieht. In Japan sind wir wohl noch nicht so weit, den Aspekt der zweiten Person, d.h. den Familien- und Freundeskreis, vernachlässigen zu können.

Deshalb ist es m. E. sinnvoll, wenn ein Entscheid über Leben und Tod bzw. ein gegenseitiges Einverständnis durch den kommunikativen Austausch dreier Personen zustande kommt: durch die erste Person der Patientenverfügung, die zweite Person der Angehörigen und die dritte Person der medizinisch Verantwortlichen (Ärzte und Pflegepersonen). Dies scheint mir kein schlechtes Konzept für die gegenwärtige Situation in Japan.

## **Schlusswort**

Im Vergleich zur „Fürsorge im Leben“ ist die „Fürsorge im Sterben“ ein Problembereich, den wir als „Polarkreis der Phänomenologie“ bezeichnen könnten. Auch wenn wir den Tod als Verhältnis des „Zwischen“ begreifen, zeigen sich in der „Fürsorge im Sterben“ je nach Person unterschiedliche, ineinander verwickelte Probleme. Was bei der Sterbe-Fürsorge die erste Person betrifft, kann sie nicht viel tun; für sie wird gesorgt und alles getan. Was ich allenfalls selber tun kann, wäre, anderen meinen Willen mitzuteilen. Aber ich glaube, es ist besser, wenn ich meinen Willen nicht ganz allein bestimme. Zu einem für alle befriedigenden, gegenseitigen Einverständnis sollte es im kommunikativen Austausch mit den Menschen kommen, die für mein Leben wichtig waren, also mit der „zweiten Person“ der Sterbe-Fürsorge, dem Familien- und Freundeskreis, und schließlich auch mit der „dritten Person“, den Ärzten und Pflegepersonen, die mich medizinisch betreuen.

Zum Ende noch eine Bemerkung. Gemäß der WHO (World Health Organisation) und ihrer Vorstellung von Palliativmedizin bedeutet „Fürsorge im Sterben“: Der Tod wird „weder beschleunigt noch hinausgezögert“. Die Palliativmedizin zielt also weder auf eine Verkürzung der Lebenszeit (Euthanasie) noch auf eine Verlängerung der Lebenszeit ab. Im Deutschen gibt es den Ausdruck „Sterbebegleitung“, dem wir

bereits im oben genannten deutschen Bericht begegnet wird. Es gibt auch den Ausdruck „Sterbehilfe“, aber das klingt, als wollte man den Patient so bald wie möglich loswerden. Deshalb „Sterbebegleitung“. „Sterbebegleitung“ heißt, an der Seite des Patienten Schritt für Schritt und Hand in Hand mit ihm zu gehen, ihn bis zum Ende zu begleiten, so dass er seinen Tod ohne Angst, gelöst und friedlich empfangen kann. Meiner Meinung nach liegt in diesem einen Wort die wahre Bedeutung von „Fürsorge im Sterben“.

## Chapter 10

# CARING FROM A PHENOMENOLOGICAL POINT OF VIEW — DECISION-MAKING IN TERMINAL CARE IN JAPAN —

### **Introduction**

Suppose here was a dying patient in the terminal stage. First, imagine that the patient was me. In what kind of world would I, approaching my end, still be living, and what kind of care could I hope for from my family, my friends, and medical personnel? Secondly, imagine that the patient was a member of my family or my best friend. In what kind of world would I be living, and how would I be attending him or her as a patient and what could I do him and her, and what would I hope the medical personnel involved would do? Thirdly, imagine that I was one of the medical staff caring for the patient. In a situation in which there was no possibility for treatment and life was coming to an end, in what kind of world would I be living as a doctor or a nurse? What could I do for the patient and his and her family and friends? As to the impending death, in the first case I would meet “my” death in the first person (of course, it is exactly impossible for me to meet my death); in the second case I would meet “your” death in the second person, and in the third case I would meet “his or her” death in the third person. There are different perspectives from which the situation can be seen. How should we make crucial decisions regarding the patient? How can we investigate such a situation from a phenomenological point of view? This is the subject of this paper.

## 1. Background: phenomenology and medicine

The relationship between phenomenology and medicine began with psychiatry. In psychiatry, Jaspers, Binswanger, Boss, Brankenburg, and others were interested in the phenomenological philosophy of Husserl, Heidegger, Sartre, Merleau-Ponty, and others, and tried to convert ideas such as phenomenological reduction, essential intuition, and transcendental functions into methods to approach the world where patients live — not to explain it from the outside, but to understand it from the inside. This so-called “psychopathology” was introduced and developed mainly by Bin Kimura in Japan. It prospered in the 1970s and 1980s under the name of phenomenological or anthropological psychiatry. But recently, with schizophrenia, the main object of their research, decreasing and becoming milder, it is said that the time of psychopathology is reaching its end. In its place, biological psychiatry making full use of gene research, brain image mapping, and epidemiological statistical research has become pervasive in psychiatry. The influential power of phenomenology in psychiatry seems to have been lost.

Such a change is not limited to psychiatry. Medicine has had a tendency to become almost a biomedical natural science since the 19th century. Nevertheless, in the 20th century, especially after World War II, as natural-scientific medicine showed both its positive and negative sides, problems of medical ethics and bioethics were discussed. Even if the word “phenomenology” itself is not used, phenomenological thoughts are pervasive in medicine, though more so in medical care than in medical science — that is, more so in patient-oriented medicine than the traditional doctor-oriented medicine. On the one hand, phenomenology is linked to the assertion of “patient’s rights,” or the change from “paternalism” to “informed consent” discussed in bioethics and on the other, it is linked to the distinction between “disease” and “illness” argued in medical anthropology.<sup>1</sup>

From a phenomenological point-of-view, the shift toward patient-oriented medicine could be considered a conversion from a medicine treating “disease” as an objective state that can be explained by medicine as natural science, to a medicine

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<sup>1</sup> Arthur Kleinman, *The Illness Narratives : Suffering, Healing and the Human Condition*, Basic Books, Inc., 1988.

treating “illness” as a subjective meaning for the patient in his/her living world. It reminds us of Husserl’s phenomenology, which insists that the sciences, seeking objectivity, forgot the foundation of their studies, i.e. the “life-world,” in which they were originally rooted, and that the sciences fell into a crisis, and that for the sciences to be saved, all scientific knowledge needs to be “put in parentheses” and scientists must return to the life-world as the place of original evidence, and found science newly once more. We must step back from the perspective of natural-scientific biological medicine seeking objectivity and universality to the patient’s life-world, and discover a medicine grounded in the life-world.

Although the main stream of medicine, as medical science, still emphasizes “EBM (Evidence-Based-Medicine),” which gives priority to empirical data (evidence) about patients’ bodies, there is also an “NBM (Narrative-Based-Medicine)” movement emphasizing the narratives of patients themselves. This movement is connected with the narrative approach or the narrative therapy that has been becoming prominent in sociology. If we go back to both their origins, we can find the idea of phenomenological sociology, founded by Alfred Schutz, a student of the later Husserl, who fled the Nazis and obtained political asylum in the United States during World War II. Although the term *phenomenology* isn’t used anymore, and the idea of a ‘narrative’, as part of a social constructivism stressing language, seems something different from phenomenology, the spirit of phenomenology is still alive in the method of letting a patient’s life-world emerge from his narrative. This “NBM” movement emphasizing patients’ narratives is now entering into psychiatry too, where medical examination by interview as oral therapy (mündliche Therapie) has been highly valued. It could be regarded as a renaissance of phenomenology in psychiatry.

I mentioned above that the relationship with phenomenology is found more in medical care than in medical science. An interest in phenomenology developed in nursing care soon after that in psychiatry.<sup>2</sup> Nowadays the influence of “EBM” is strong also in nursing studies, but phenomenological studies in nursing continue to be

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<sup>2</sup> The article “Nursing” of *Encyclopedia of Phenomenology* (Eds. Lester Embree et al, Kluwer Academic Publishers, Dordrecht/Boston/London, 1997) says, “Interest in phenomenology among nursing scholars developed rapidly during the late 1980s and 1990s.” But the article “Nursing and phenomenology” in the Japanese *Encyclopedia of Phenomenology* (Eds. Kida Gen et al, Kobundo, Tokyo, 1994) mentions also pioneering works published in 1960s and 1970s.

carried out as qualitative research rather than quantitative research, under the name of hermeneutic phenomenology or the phenomenological approach. Among such studies in nursing, I would like to mention only one — an outstanding study of Yumi Nishimura's: *Talking Body — Phenomenology of Nursing Care*.<sup>3</sup> Corresponding to phenomenological studies on the part of researchers in nursing, there is a developing interest in nursing care on the part of researchers in philosophy. In this paper, I would like to discuss the phenomenology of care in a wider sense than just nursing care.

## 2. Phenomenological anthropology of Caring

In phenomenological terminology, caring in the widest sense is a kind of intentionality of consciousness, namely an intentionality which functions more in the dimension of action than in the dimension of cognition, as well as an intentionality which is not closed within the self but relates to the other. If care directed toward the other does not lead to his or her satisfaction, by no means can it be considered care in the true sense — even if it leads to *self*-satisfaction. Insufficient care becomes no more than a small kindness, and excessive care becomes only an inappropriate effort. Neither one nor the other becomes adequate care. There is always a possibility of discrepancy in giving care and receiving care.

As is often introduced in books dealing with the subject of care,<sup>4</sup> Martin Heidegger in *Being and Time* characterizes the fundamental way of human being as “caring (Sorge),” and also characterizes it as “Being-in-the-World (In-der-Welt-Sein),” as well as “Together-Being (Mittdasein).” Care means that we are always in the world and relating to the other. More exactly, we can say that I refer to the other, and at the same time the other refers to me, that we live in relationships of “caring and being cared for.” Caring requires relationships between human beings, or in Husserl's

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<sup>3</sup> Yumi Nishimura: *Talking Body — Phenomenology of Nursing Care* (Japanese), Yumiru-shuppan, Tokyo, 2001.

<sup>4</sup> E. g. cf. Patricia Benner / Judith Wrubel: *The Primacy of Caring — Stress and Coping in Health and Illness*, Addison-Wesley Publishing Company, Inc., 1989.

terminology, an intersubjective way of being in the “life-world (Lebenswelt),”<sup>5</sup> or in Bernhard Waldenfels’ or Bin Kimura’s terminology, the phenomenon of “between (Zwischen)” between persons.<sup>6</sup>

However, this does not imply a homogenized community of “us.” The intersubjective world phenomenologically understood is a multi-perspective world with views spreading out radially from the zero of “Now-Here-I.” It is a non-homogeneous world that constitutes itself from an exchange of standpoints and communication between this “me” and “others” holding different perspectives. While the word *perspective* was originally used in a spatial sense, Husserl used it also in a temporal sense; however, we can also use it in a personal sense. This multi-perspectival world signifies the world which includes a *spatially* top and bottom, right and left, front and rear, far and near, a *temporally* past, present, and future, (temporally) far and near, and a *personally* the differences originating from interaction among the first, the second, and the third person.

To consider the theme of “caring” phenomenologically, we must take the relationships among human beings and the personal nature of the relationships into consideration. When we are born, as well as when we die, we always do so among such relationships and personal perspectives. Birth as well as death, namely if I may speak from a Buddhist point-of-view, birth, aging, illness, and death (*shiku* 四苦), are events in relationships or in the *between* (Zwischen) and with personal differences. Arthur Kleinman distinguished between “disease” as an object of objective medicine and “illness” as a lived subjective experience in his work *The Illness Narratives*, in this work, we can find the differentiation between a “disease” grasped in the third person and an “illness” lived in the first person. Vladimir Jankélévitch made a distinction between death in the first person, the second person, and the third person in *La mort*,<sup>7</sup> and here we can also find a phenomenological consideration in the background.

<sup>5</sup> Shinji Hamauzu: *Husserl’s Phenomenology of Intersubjectivity* (Japanese), Sobunsha, Tokyo, 1995. If I can make a remark about the use of the expression “phenomenological anthropology,” Husserl sketched several ways to the transcendental phenomenology, one of which was “phenomenological psychology.” Studies on the same dimension should be “phenomenological sociology” and “phenomenological anthropology,” a trial of which is the theme of this paper.

<sup>6</sup> Bin Kimura: *Hito to Hito no Aida* (Japanese), Kobundo, Tokyo, 1979.

<sup>7</sup> Vladimir Jankélévitch: *La Mort*, Flammarion, Éditeur, Paris, 1966.

When considering the Buddhist *ku* (“suffering”) involved in “birth, aging, illness and death,” we can designate the suffering person in the first person, someone speaking with *you* in the first person as the second person, and people surrounding both persons at a distance and providing care as the third person.

Similarly, personal differences come into play in medical treatment, especially in the care of terminally ill patients. The question as to who is concerned with a person’s death arises. In medical scenes it is the patient who suffers in the face of death in the first person. If illness or death is an event in a relationship, we can also call his or her family or friends (i.e. those who call him *you*) one of the persons concerned.<sup>8</sup> Furthermore, we can say that medical personnel who treat terminal illness are participants in the event, third-person participants. (If criminal “euthanasia” occurs, the medical staff involved becomes connected to the crime.)

As personal differences and perspective play a big role also in medical situations, there is a need for those involved to integrate the differences through communication with each other. In reality, the communication does not always succeed; it is often the case that divisions remain and opinions conflict. In those cases, it is important — speaking from a phenomenological point of view — that this difference of person has an order of precedence. It is the suffering and dying patient in the first person who is the most fundamental and important. Of secondary importance is the person who stands in the “you”-relation with the patient. And last, but whom we must not ignore, are the medical personnel who make efforts to rescue the patient and accompany him or her. In order not to lose from sight such a precedence order, we need to communicate with each other, paying mutual attention to each point of view.

Such a consideration overlaps with problems of bioethics. In bioethics, one discusses, on the one hand, problems involving legal issues of rights, duty, and justice; and on the other hand, problems in care such as a patient’s QOL (quality of life) or “cure and care.” The discussion of what should be the basis of ethics — that is, whether justice and rights should be the basis of ethics or caring and responsibility, is also dealt with in bioethics. Next, I would like to consider the contrast between the “ethics of justice” and the “ethics of care” from a “phenomenological point of view of

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<sup>8</sup> We have no custom to use the word *you* to address each other. A family does not always have an intimate relationship in the second person.

caring.”<sup>9</sup> But owing to limited space, I would like to hurry to one concrete problem of care — terminal care.

### 3. On terminal care in Japan

In March of the last year, incidents in a municipal hospital in Toyama Prefecture were reported on in the media almost every day for several months. Seven patients dying of cancer and in the terminal stage were removed from their artificial respirators. I would like to mention here the following three points from the information reported: Firstly, there seemed to be a silent, unwritten agreement concerning the patient’s will and family consent. Secondly, the head of surgery in the concerned department had probably made the decision to remove patients from respirators alone, without checking with other medical staff. Thirdly, voices calling on hospitals or the nation to establish rules increased.

In regard to organ transplant after brain-death, we at least have one law in Japan, though it is not such a good one (“The organ transplant law” introduced in 1997); in connection with this law there are also “Regulations for execution of the law,” “Application guidelines,” and “Manual for legal judgment of brain-death.” Although several problems still remain, rules were established which allowed, up to the beginning of this September, 60 cases of organ transplants after brain-death was determined. Worldwide, the character of this law is rare, because it makes possible a transplant after brain-death not by defining brain death as the death of the person himself uniformly, but rather via two presuppositions — first, the expression of the patient’s will in writing, and second, the agreement of his or her family — and after ascertaining certain medical conditions such as brain-death. (In other words, without fulfillment of the two presuppositions, not only will an organ transplant be disallowed, but even a judgment of brain-death cannot be made.) The judgment of brain-death (in the third person) only being carried out when both presuppositions — the expression of the patient’s will (in the first person) and the agreement of his or her

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<sup>9</sup> From “Anthropology of Care” cf. Shinji Hamauzu (ed.): *Introduction to the Anthropology of Care*, Chisen-shokan, Tokyo, 2005.

family (in the second person) — have been fulfilled could be said to reflect Japanese culture. But, on the other hand, because even the judgment of brain-death cannot be made if either the patient's will or family agreement is lacking, it leaves behind unresolved problems in many cases of terminal care after "brain-death" (we can't call it "brain death" because we aren't legally allowed to make a judgment).

Unlike organ transplant after brain death, there are no rules in Japan for medical treatment in terminal cases. There is only the criminal law that declares assisted suicide a type of murder. Beyond it, however, there are only three conditions for stopping life-prolonging treatment (death with dignity) and four conditions for legitimate euthanasia — all of which arose from judicial precedent from a case involving the hospital affiliated with Tokai University in 1995 — and are obliging to a certain degree. Nevertheless, I am not of the opinion that a law should be introduced as the former Japanese Society for Euthanasia thought, or such a law for euthanasia as in the Netherlands and Belgium, or a law for death with dignity (assisted suicide) as in the U.S. state of Oregon, because such laws would "work" differently in Japan than in countries in which there is a culture of individualism and the family doctor system works well. A law in Japan should be one that takes Japanese culture and the Japanese medical system into consideration, just as the organ transplant law does. In my opinion, there could be, in the treatment of terminal cases, a rule similar to the one in the case of brain death and organ transplants.<sup>10</sup>

One could ask how we can make the best use of the two Japanese conditions of patient's will and family agreement (putting aside medical judgment) as are established in the case of organ transplant. Corresponding to donor cards for organ transplants, there is a "Manifesto of death with dignity (living will)," which the Japan Association for Dying with Dignity has made. Its popularity is spreading, with the number of registered already exceeding 110,000. However, this manifesto contains problems in all three of its points (unfortunately, here I do not have space to enter in to them here). Also, the one-sided style of this manifesto (it includes neither family signatures nor a space for doctor authorization) is not obliging legally at all, and even if a doctor wishes to respect the patient's will, he will have difficulty doing so in fact.

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<sup>10</sup> It is pointed out that Japan is late in establishing laws related to bioethics, including laws in the field of reproduction-assistance.

I rather find the patients' "advance directives" far more recommendable. They have even more precise contents, make provisions for two representatives (family members possible) and a doctor to sign, and make detailed choice about methods of treatment possible. There is also a blank for free expression of any personal wish. Although some problems still remain with the use of these advance directives, I believe they should be given a legal footing.

In May 2007, the *Japanese Ministry of Health, Labor and Welfare* — published "Guidelines for decision process of medical treatment in the final stage."<sup>11</sup> It states: first, a team of caregivers composed of experts from multiple medical fields should, taking into consideration the patient's personal decisions, make a careful decision — one that is medically reasonable; secondly, as much as possible, a patient's pain and discomfort should be reduced, and comprehensive medical care that offers mental and social support for the patient and family should be provided; thirdly, in no case should one involve active euthanasia or assisted suicide in medical treatment. Furthermore, one should make judgments on terminal medical care while differentiating between the following two cases: one in which the patient's will can be ascertained, and one in which it cannot.<sup>12</sup> In the first case, the patient's will as expressed in an informed consent should be the basis for further and sufficient discussion between the patient and the medical caregivers, through which the patient's will is reconfirmed — and his thoughts on treatment, assuming his condition changed, were also clarified. In the second case, caregivers should ascertain as much as possible the patient's will through conversation with his or her family or others. If that proves difficult, caregivers should, while consulting the family, select the best treatment for the patient. Finally, in a case in which the patient and the medical team cannot come to an agreement, or in which opinions of the team are split, the team should establish a committee of different experts in the hospital and ask for council.

It is pointed out that because the terminal stage of an illness is not clearly defined — who makes the judgment and with what criteria? — the Ministry's guidelines might be not useful in clinical situations. Nevertheless it can be considered

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<sup>11</sup> <http://www.mhlw.go.jp/stf/seisaku/seisaku-000010521-11.html>

<sup>12</sup> The case where patient's will can't be ascertained includes various cases, such as senile dementia, brain-death or vegetative states, newborn baby with heavy disabilities, psychic disorders, intractable neuro-diseases e.g. ALS. Exactly we had to discuss them differently.

a small but important step in care for terminal illnesses; though not a law, it offers guidance that medical personnel should follow. Besides its main text, this guideline contains an explanatory part that introduces information that might have been discussed in the committee. I would like to point out some important issues mentioned in it: (1) What kind of states should be designated terminal is a matter which requires appropriate and adequate judgment on the part of the medical care team — judgment based on patient's states; (2) *Family* implies a person whom the patient trusts and who assists him or her in the final stage; it is not necessarily limited to mean only a relative in law, but includes persons in a broader range. (3) If the patient, his or her family, and the medical care team arrive at an agreement on care, it should be respected as the best medical care for the terminal patient. Although it is not stated in the main text of the guideline, it is implied that the ultimate goal is to reach agreement among the patient, his or her family (in the wider sense), and the medical care team.

Just as when discussion was beginning on this guideline, the Japanese translation<sup>13</sup> of *Human Death and Self-Decision, Interim Report of Council Ethics and Right of Modern Medicine, Advanced Directives* (2004)<sup>14</sup> of the German Federal Parliament was published. This report made clear that the situation in Germany was different from that in Japan.

#### **4. Discussions about advance directives in Germany**

This report states that the “collapse of the traditional family” is a key feature of contemporary German society. With this “change in society” as background, the report states: “Such advance directives make sense, as far as we can clarify in writing agreed-upon opinions and matters which family members discussed with one another. For such reasons, the report proposes a concrete law to regulate patient's advance directives legally.

In comparison to the above-mentioned guideline in Japan, it strikes me that the

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<sup>13</sup> Transl. By Tatsu Yamamoto et al., Chisen-shokan, Tokyo, 2006.

<sup>14</sup> <http://www.bundestag.de/parlament/gremien/kommissionen/>

German report not only proposes rules for a patient's advance directives, but also tries to think the problem through from the ground up and in a wide context — what can be characterized as typical German thinking. In the report summary, the following is stated: "It is crucial to improve the system for accompanying seriously ill and dying people as well as to enrich the palliative care and the hospice organization. The debate on patient's advance directives must always be embedded in this context." The report's introduction includes the following statement: "Questions related to the patient's advance directives must be seen in the total context of accompanying the dying (Sterbebegleitung) and palliative care." Moreover, the context is widened, as far as it is not yet well handled in this report, as follows: "The further going questions of accompanying the dying, including the satisfaction of physical, mental, social, and spiritual needs, are not grasped by many advance directives." This is something that needs to be understood clearly about advance directives.

This report confirms the right to make decisions by oneself (self-decision) on the one hand — "making decisions by oneself is a basic human right" — but on the other hand, does not forget to add that it should not be considered in isolation. More specifically it reads: "Patients' advance directives should be interpreted giving consideration to more general ideas, such as the freedom of individuals, human welfare, duties of doctors and nurses, rules based on the right of patients, medical effectiveness and so on." This is a different position than the one taken by those in the field of liberal bioethics in English-speaking regions, who puts priority on the right to make decisions concerning oneself and recognizes the individual's will as much as possible — as long as it does not damage others.

I am reminded of the report preceding the above-mentioned one, that is, *Human Dignity and Genetic Data — Final report of the commission of the German Federal Parliament on the law and ethics of the modern medicine* (2002).<sup>15</sup> First, it mentions the concept of human dignity (*Menschenwürde*) as outlined in the first chapter of the German Constitution, and then, from that historical perspective, it defines human beings as "both free and dependent." The report further reads: "People have a physical existence, they are imperfect and vulnerable beings, and we must guarantee that people who need care are respected." "As human beings, they need not possess any

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<sup>15</sup> Japanese Translation. Transl. by Jun Matsuda et al., Chisen-shokan, Tokyo, 2004.

special qualities or abilities to have their rights to human dignity guaranteed and protected. Whether old or young, strong or weak, ill or healthy — every person has the right to have his or her dignity respected.” “Every person is dependent on the support of others, in many phases of his or her life (e.g., childhood, illness, old age), in order to have his or her individual freedoms guaranteed.” Here, the point of view that not only are people independent, having the right to make decisions by themselves, but also that people are weak, vulnerable, and imperfect beings who must rely on the assistance of others, is made clear. The attitude exhibited in this German report, then, is that patients’ advance directives should be considered keeping in mind both sides of human beings.

## 5. How about it in Japan?

I would now once again like to focus on today’s situation in Japan and examine the “Report from “On terminal care again,” by the the Ninth Meeting on Bioethics of the Japanese Federation of Medical Doctors, published in February of the last year.<sup>16</sup> To me, what is important to note in the report is not only “respecting patient’s will,” but also “discussing the matter with medical personnel so that also the family understand the matter and come to a consent.” The report states: “In terminal care, especially when the selection of treatments becomes a matter of life and death, or when treatment at home or in an institution are options, the decisions involved are not only issues for the patient, but also for the family supporting him or her. It is desirable that the patient not make decisions alone, but to make a decision after sufficient discussion with family.”

This Japanese report also points out some problems with patients’ advance directives. For example, “Patients’ expectations are not always reasonable.” “There are cases in which patients’ situations change from the time their advance directives are written to the time the directive is to be followed.” “The manner in which advance directives are accepted needs to be examined.” “There will always remain a variety of opinions regarding life expectancy forecasts or possibilities for recovery.” These

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<sup>16</sup> <http://www.med.or.jp/nichikara/seirin17.pdf>

remarks show that a check of medical validity is necessary for patients' advance directives.

In August of this year, an interim report was issued by the above-mentioned Meeting on Bioethics: "A proposed guideline for medicine in terminal cases" — and opinions regarding it were solicited through the end of this September.<sup>17</sup> There are no big differences in fundamentals from the guidelines of the *Ministry of Health, Labor and Welfare*, but the following aspects of the August proposed guidelines deserve attention: (1) "Even in cases in which confirmation of the patient's will is impossible, if there is a 'patient's advance directive' the medical care team should consult with the family and determine whether or not it is still valid." This is the first guideline to mention patient's advance directives. (2) In all cases, confirmations, agreements, and disagreements among family and others should be in writing. (3) In cases in which the terminal patient refuses life-prolonging treatment, or in cases in which the patient's will cannot be ascertained and the family refuses life-prolonging treatment, a system needs to be created that ensures that the act of refusing life-prolonging treatment leads neither to civil nor criminal responsibility. In each of these points, despite its call to systematize respect for the will of both patients and families, this latest proposed guideline displays an intent to defend and protect doctor's rights.

I would like to come back to the problem of family in Germany. I've said that the German report started off by mentioning the "collapse of the traditional family." Although expressions like *family* or *relatives* (*Angehörige*) appear in it, they are not stressed; rather, expressions like *agent* (*Betreuer*) or *representative* (*Bevollmächtigter*) are prevalent. Since this report tries to focus on the relationships among people — or the interdependence of people — it exhibits a different position from the one found in bioethics in English-speaking areas, which greatly emphasizes the right to make decisions for oneself. Nevertheless, it holds that this relationship or interdependence cannot be understood any more in the form of family. In Japan, however, we cannot yet, in my opinion, throw away the point of view of the second person of family, relatives, and friends.

Thus, in Japan, advance directives of the patient (the first person), the consent of his or her family (the second person), and the judgment of medical personnel (the

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<sup>17</sup> <http://www.med.or.jp/nichikara/iken/info.html>

third person) all have their place — and it is necessary for these “three persons” to communicate mutually and to create a consensus through discussion. In my opinion, this is not, for Japan, a bad way to approach the issue.

## Conclusion

Unlike care for “living” persons, care for “dying” persons seems to present issues which relate to the extreme north of phenomenology. Even if death is considered an event that occurs in a relationship, caring for a dying person in the first person (that is, myself), caring for a dying person in the second person, and caring for a dying person in the third person present different problems, though those problems are related. The *I* who is caring for a dying person in the first person cannot do a lot. What the *I* can do is leave a record of his will to others in advance. But the *I* cannot decide his will only by himself, but as a part of human relationships in which he has lived up to now, above all, in relationships with family or friends — who themselves stand in the position of caring for a dying person in the second person — and in relationships with medical personnel — who stand in the position of caring for a dying person in the third person. The *I* must come to an understanding with others through communication.

I would like to say one more thing. According to the idea on palliative care of the World Health Organization (WHO), “caring for dying persons” means: “We should neither assist in accelerating nor assist in delaying death.”<sup>18</sup> Palliative care aims neither at euthanasia nor at prolonging survival time. In German, there is an expression, *Sterbebegleitung* (“accompanying the dying”) — this appears in the abovementioned report — which contrasts with the expression *Sterbehilfe* (“helping the dying”). *Sterbebegleitung* means keeping in step with the patient as he approaches death, and being with him at the moment he, with full spirit, welcomes death. The third person also “supports” the dying. This, then, is my opinion on caring for a dying person.

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<sup>18</sup> WHO: *Cancer pain relief and palliative care*, WHO Technical Report Series No.804, 1990.

## Chapter 11

### NARRATIVE AND PERSPECTIVE

The term “narrative” refers to both the “narrated story” and “narrating act”. Compared with an already finished story, a narrating act in the state of being born lies in a so to speak, in a magnetic field where a narrator narrates to a listener/listeners. The narrative has the point of view of the narrator and is narrated in a spatial and temporal perspective of where and when he/she begins and ends his/her narrative. Listening to this narrative gives us an important clue in order to approach to in what life-world he/she lives, what he/she thinks and values. However, the narrator doesn't narrate everything what he/she experiences and thinks about. He/She selects what he/she finds worth to narrate and makes his/her story. The truth for the narrator is not always true for everybody who experienced together with the narrator. It doesn't mean that the narrator told a lie. Even if the narrator told what he/she found true from his/her perspective, the other who experienced the same event from other perspective could experience it totally differently. Certainly there is a space into which a falsehood could enter. Or, the listener could understand it in a totally different perspective what the narrator tells. Because there could be a gap between the narrator's perspective and the listener's one. That could build a hotbed which could give birth to a lie. In my following speech I would like to seek how narrative and perspective could conceive truth and falsehood. Since I've been engaged in phenomenology, especially the phenomenology of intersubjectivity, as well as in anthropology, especially anthropology of caring, I would like on one side to welcome such a movement to emphasize narrative, but on the other side feel worry about its attitude to take the focus on linguistic “narrative” exclusively. The point of my speech lies in making clear this ambivalence against narrative approach.

## 1. Attentions to “narrative” in various fields

The theme “narrative” has recently attracted researchers’ attentions in various fields. What attracted researchers’ attentions to the act of “narrative” in philosophy was the “narrative theory of history” developed in A. C. Danto’s work *Analytical Philosophy of History* (1966), which was parallel to Thomas Kuhn’s work *The Structure of Scientific Revolution* (1962), which brought the paradigm change from positivistic to hermeneutic view of science in natural sciences. Danto’s work has brought the similar paradigm change in human sciences. According to Danto’s idea the basis for historical description is not an “ideal chronicle” where every event is exhaustively written down, but a “narrative sentence” which describes past events as such, not as participants experiencing the events directly report, but as historians re-describe them in the light of subsequent events that participants didn’t know. In Danto’s work there was also the idea of “point of view” of narrative that “historians view an act in the temporal perspective”.

In Japan we find the first discussion about “narrative” in philosophy in the volume 8 of the series *Adventure of Modern Philosophy* (1990). The article at the beginning of this volume was NOE Kei-ichi’s “Introduction to the theory of narrative acts”. He began by characterizing human beings as “narrating animal” or “animal obsessed by desire to narrate”, based on the above-mentioned Danto’s discussion, confirmed that “experiences become experiences only by narrating” and called the “conceptual equipment to transmit experiences and make them common” as “narrative”. In the same year a Japanese philosopher SAKABE Megumi published a pioneer work of modern theory of “narrative”, *Katari* (1990). He piled up an original thinking within a space of Japanese language in spite of being led by P. Ricœur’s work *Temps et récit* (1983), and discussed the theme “narrative” from a fresh point of view, such as “narrating” and “deceiving”, “narrative” and “song”. It is very interesting for our discussion: His theory of double structures that constitute the scene of narrative, developed by the well-known fact that “narrating” leads to “deceiving”, and his discussion that “sciences idealize so to speak <non-personality> being totally free from any specialized point of views”, and that “poems have their character of utterance as <multi-personality> or <primordial-personality>.

In the field of psychology the Japanese psychologist KAWAI Hayao published

his work *Narrative and Human Sciences* (1993), and, referring SAKABE's work, discussed narrative and psychotherapy. He claimed that "a narrative has a plot" and, it means that "I am inserted in it", and continued that "the language of sciences will tell facts as they are, whereas the language of poems will do very difficult trials to tell my inner experience, e.g. my looking at a glass, in the relationship with <I>, and yet to others".

On the other hand, apart from these fields of philosophy and psychology, the theory of "narrative" that A. Kleinman's work *The illness narratives: suffering, healing and the human condition* (1988) developed in medical anthropology, has influenced widely on medicine, nursing and welfare studies. He distinguished between "disease" that is viewed from the medical point of view and "illness" that is lived experience from the point of view of patients. Since "patients arrange their experiences as personal narratives", according to him, "it is important for care-givers to be present at narratives of their lives, to admit correctness of their interpretation and to support their value". He asserted that caring begins with listening to the narrative of illness. Being prompted by this medical anthropology, the studies from the outside of medicine, it appeared a corresponding movement from the inside of medicine.

In the field of medicine and health care, in the 1980's, accompanied by the development of digital database of medical information, e.g. by MEDLINE of the National Library of Medicine and with the development of the epidemiological and statistic methods, there appeared the assertion that the evidence for selection of a treatment "must be looked for in observations and experiments based on correct methodology". Since 1990's the idea of "EBM (Evidence Based Medicine)" has spread rapidly, that in selection of a medical treatment, based not on a theory or an experience or a judgement of authority; but rather on firm epidemiological evidences, we must pass the scientifically best judgement. However, as if following this movement, in the second half of 1990's, the idea of "NBM (Narrative Based Medicine)" has appeared, that requires a paradigm shift against "evidence", "statistics" and "scientific character". According to the latter idea human beings live their original "narrative", and even "illnesses" are a part of their narratives. Taking narratives of patients seriously and utilizing dialogues to clinical practice are regarded as an important obligation of medicine. But this NBM is not regarded as taking the place of the EBM, "not as what are counter to each other, but as what complement each other".

In the field of clinical psychology and clinical sociology, in the similar time (the second half of 1980's), instead of the system theory that takes family as a system, the "narrative therapy" (reconstruction of reality by "narrative") based on social constructionism has spread. This social constructionism, originally an idea of sociology, became a movement that asserts the important role of "narrative" in caring or helping and is called as "narrative approach". The Japanese sociologist NOGUCHI, who edited *The World of Narrative Therapy* (1999) and published *Caring as Narrative — to the World of Narrative Approach* (2002), advocated "a narrative revolution in clinical fields" and expressed that "in the clinical world it is now changing from 'the time of technology' to 'the time of narrative'".

Even in the field of psychiatry, where the psychotherapy originated, there is a tendency to re-examine the concept of the "narrative". The Japanese psychiatrist FURUKAWA(2003) gives on the one side "a theoretical outline of diagnosis studies in psychiatry from the standpoint of EBM", on the other side regards it as "what should converge to reading the story of patients" and called NBM as one of the two wheels that constitutes EBM. The Japanese psychoanalyst KITAYAMA (2004) said that "a work to draw out of clients' 'narrative' and to spin 'stories' is originally none other than a reconstruction of the past, and is regarded as a familiar work for therapists intending to practice a psycho-analytical psychotherapy". Also, the Japanese psychiatrist KATO(2005), who has been engaged in psycho-pathological investigations of schizophrenia and manic-depression, discussed that it is important "to insist that in the time where EBM is called as a golden rule the approach of NBM is ultimately alpha and omega for psychiatric clinic, and to consider how to listen to narratives of schizophrenia patients and how to correspond them by psychotherapy in a wide sense".

Turning our eyes toward the field of nursing studies, P. Benner (2004), who is famous with her phenomenological theory of nursing, states that "the attitude of nurses' listening to promotes restoration of patients", and that "it is necessary to put the medical intervention into the situation of patients and make it narrative". She advocates "narrative as a method to grasp the nursing practice", insists that the method of narrative is necessary to take the practical knowledge of nursing and to think critically, and pays attention to not only narratives of patients but also narratives of nurses. Finally in the field of caring, the Japanese psychiatrist and specialist in dementia OZAWA (2003), using the term "life-world", asked a question

“in what a world persons suffering dementia live, what they see, think, feel and what inconvenience they live”. In an extension of this idea, in his article “Caring for dementia as narrative” (2004), he states that “I wanted to show the core of my theory of caring for dementia, not to receive words and behaviors of persons suffering dementia only superficially, but to interpret them as a story that is spread behind them”, and referred “narrative therapy (therapy that respects narratives of each person)”.

I said that against such a movement to emphasize “narrative” spread in these various fields I would like on one side to welcome it, but on the other side feel worry about it. To answer why I would like to welcome it, the above-mentioned social constructionism came from Berger & Luckmann (1966) who inherited the stream of phenomenological sociology originated by Alfred Schutz. He sought refuge in the United States after he had a scientific exchange with Husserl in his later years. In the idea of social constructionism that “the reality of ordinary life appears for us as an intersubjective world, namely as a world that I have with others in common”, I find a heritage of phenomenological ideas, even if it is in a different style. On the other hand, to answer why I worry, social constructionism, especially with the idea of the “linguistic construction of reality”, emphasizes paying attention to language so that it has a tendency to focus solely on narrative by words. If we say that “reality” doesn’t exist objectively but is mediated by language and others, and is constituted intersubjectively, we can find something common with Husserl’s phenomenology. But against lingua-centrism which will reduce everything into language I would like to keep a distance. In my opinion we can admit the nonverbal dimension of body and investigate the “constitution” functioning already there. In other words, we can distinguish between the dimension of “linguistic articulation” and the one of “bodily articulation” in the “constitution” of the world.

## 2. Phenomenology of “perspective”

Although I cannot approve the lingua-centrism conceived in the “narrative” theory without hesitation, I would like to evaluate its emphasizing of “narrative” action on the distinction between nominal “narrative” and verbal “narrating”. That a

“narrative” is narrated from the perspective of narrator’s point of view is important, and in this sense we can say that the “narrative” theory has something common with the fundamental idea of phenomenology. Moreover, a “narrative” cannot stand up solely with a narrator, but demands a listener who has a perspective more or less different from the narrator’s one, therefore “listening to the narrative” cannot but have not only overlap but also difference between both perspectives. In this sense, we can find something common with phenomenology. However, according to phenomenology this phenomenon of perspective is a structure that appears already in the bodily dimension, without being “narrated”, in this sense the phenomenology part from the lingua-centrism.

The perspective in this context is not the one like an artistic technique in pictures (perspective drawing), but the one as a structure that the relationship between the *<I>* and the world appearing for me, namely that *<I>* am situated *<here>* with *<my>* body and can do nothing but perceive the world from *<here>*, then the world can do nothing but appear in the perspective from *<here>*. That I call as “perspective”. Therefore the world has the spatial structure that it has “orientation” such as “upper” and “lower”, “left” and “right”, “front” and “rear” from *<my body>*, and the depth such as “near” and “far” and correspondingly “big” and “small”. Accordingly “this side” of an object is seen, whereas “back side”, “another sides” and “inner side” are not; objects “before me” hide objects “behind” them. These are also derived from the same structure of perspective. Moreover, being connected with them, from the interest or intentionality that *<I>* have, an object floats up as “a figure on the ground”, in a distinction from “circumference”, “background”, “horizon” and finally the world as “horizon of horizon”. “Perspective” expresses such a structure of the relationship between the world and *<I>*.

Here I would like to add the term “kinesthesia” that Husserl used, a word combining both Greek words of “kinesis (movement)” and “aisthesis (sense)”. That *<my body>* as the origin of the above-described non-homogenous and non-Newtonian space has a constitutive function by its “kinesthesia” is mentioned in Husserl’s *Ideen II*, and later inherited and developed by Merleau-Ponty. From this it is recognized that the above-mentioned perspective space is not static, but dynamic, and that the structure of “far” and “near” is only possible by the kinesthetic “I move”.

At the same time it also turns out that I mentioned just the spatial perspective,

but that the relationship between the world and *<I>* has a structure of temporal perspective too. Not only *<I>* am situated spatially *<here>* because of *<my body>*, but also temporally *<now>*, therefore the time can only appear in the perspective from this *<now>*. The past can be talked about only in looking back from the *<now>*, the future also only in looking forward from the *<now>*. Moreover this *<now>* is by no means each moment as a point, but is *<now>* accompanying horizon of “just ago” (retention) and “just soon” (protention), namely the “living present”. It flows continually, settles down and accumulates. We live in such a perspectivistic temporal structure. This is a point of Husserl’s theory of time. He raised instead of the homogenous Newtonian time and space a non-homogenous phenomenological theory of time and space spreading from the origin of *<I-now-here>*.

In my paper “schizophrenia” (1998) I discussed that there are two types of psychoses as ideal types. On the one hand a patient E is amnesia of whole life and asks “Where is here? Who am I?” It means, although E has lost own whole memory till then, as long as E asks so, he/she has understanding of what means “here” and “I”. This patient has lost the data that should be connected to this fundamental understanding. On the contrary, a patient T lacks the living sense of *<I>*, inspite of various data, and cannot understand whether they belong to him/her or to others, nor which data belong to him/her. T lacks the living sense that *<I>* am living situated *<here, now>*. The disorder of the patient E lies in that data on the “empirical” dimension have been lost, whereas there remain yet the “transcendental” function of *<I-now-here>*. On the contrary, the disorder of the patient T belongs to the “transcendental” dimension, and lacks the fundamental sense which connects *<me>* with *<here, now>*. This was only my raising a question what about such a distinction as ideal types, because I’m no clinician that talks with concrete data of patients. I wanted only to focus on the “transcendental” function of *<I, now, here>*.

This problem of the “transcendental” structure that the world appears from the perspective of *<I, now, here>* lies on a different dimension from the “empirical” structure that the perspective of “I” (the narrator) is different from the one of “the other” (the listener), and that there is a lag. In the following I would like to start from the state that there is a difference between the narrator’s perspective and the listener’s one, and to discuss how to adjust them and to come to an agreement. Therefore here I cannot enter into how these different perspectives are generated.

Certainly genetic spoken, it is not the case that there are at first both perspectives, then they need to be exchange, but it is the case that there is at first a perspective indifferent between “I and the other”, then it is differentiated into the perspective of “me” and at the same time the other’s one. Surely it is the genetic order, but here I would like not to enter into such a discussion about the ‘genetic problem’, but to go further into the problem of perspective in “narrative” after confirming that the difference of perspective appears before the linguistic dimension, already in the pre-linguistic and bodily dimension.

### **3. Perspective of “narrative”**

A “narrative” has a perspective. It means that the narrator can only narrate in the above-mentioned spatial and temporal perspective, and that the dimension of “linguistic articulation” depends on the one of “bodily articulation”. Language certainly articulates the formless world and gives forms to it, but it can happen only based on the world that is already perspectivized and articulated through/with body. The perspective of “narrative” can be realized only based on the spatial and temporal perspective from the origin of <my body>. Since the latter has been elucidated by phenomenology, the “narrative” can only elucidate the dimension of language based on the phenomenological analysis.

Here is a clue to discuss the truth and falsehood of a narrative. It is possible that what seems true from a perspective seems false from another perspective. Truth and falsehood of a narrative depends not only on the spatial and temporal perspective, but also on the perspective of narrative. For instance, something that seems a circle from an angle can seem a rectangle from another angle. If a person who sees the thing from an angle says based on the appearance “there is a circle”, another person who sees the same thing from another angle thinks that the first person tells a lie, because this second person thinks “there is a rectangle”. The same thing can be talked in such terms of aspects and/or contexts. For example, although a figure in the context of rabbits seems to be a rabbit, it can also seem to be a duck in the context of ducks. A person narrates “there is a rabbit”, whereas the second person narrates “there is a duck”, and both abuse the other to be a liar. To “narrate” without noticing the difference of

the spatial and temporal perspective causes the disagreement of truth and falsehood.

What I just called “truth and falsehood”, can be understood also as “reality and fiction”. The “narrative” doesn’t narrate the “reality” as it were, but on the one hand narrates it “too few” by not taking up much, on the other hand narrates it “too much” by adding e.g. a causal relationship. “Narrating” reality “too few” or “too much” is different from “swindling” and “fiction” only with a hairbreadth.

Such “too few” and “too much” of “narrating” happens already in the dimension of the bodily perspective. Husserl said: “The outer perception is a persistent presumption to accomplish what cannot be accomplished from its essence.” Take seeing for instance, we don’t accept simply everything what is given, on one hand we don’t see everything to be given, on the other hand not everything we see is given, namely we see more than given. As in the “narrative”, so in the “seeing” we see “too few”, on the other hand we see “too much”. And this is just what the term “intentionality” means, a term that Husserl learned from Brentano.

If we discuss the perspective of “narrative” different from the spatial and temporal perspective, it is characteristic that the “narrative” has a “beginning”, a “plot” and an “ending”. As a prototype of language lies in classification or grasping that pulls out an object from the world or the surrounding, so a “narrative” states a “beginning” in an event out of innumerable events, gives a “plot” in a situation where innumerable plots are thinkable, puts an “end” in innumerable events and cuts off a story. It would be a perspective that we get through drawing a line. As is often said, in a diary we don’t write down everything what happens on the day, but only those events what are vividly memorable, especially attract our attention, and we want to keep in mind. Although time flows day after day and various events happen, if we “narrate” our experience, we bind several events to a “plot”. Although it was possible with any event we end our “plot”, we take out an event to “end” it. In such a way a “narrative” comes into being.

However, we may not forget that a lot of “un-narrated” events remain in the circumference of the “narrative”. The reason why the narrative theory of history was criticized came from the point that we must listen to the voice of “un-narrated” people. However, because I cannot enter into this discussion, here I would like only to confirm that the process of those events could be narrated with another “beginning” through another “plot” and with another “end”. That “narrating” is at the same time “swindling”

from the beginning originates from such a situation. “Narrating” a process of events with a “plot” is just “swindling” for a person who sees another “plot” in the same process. “Narrating” truth from a perspective becomes “swindling” falsehood from another perspective. It will be meaningless to ask whether it is true or false without perspective.

One of the narrative theories, which make use of these circumstances, is called as a “rewriting method of narrative” (White & Epston). It is to turn one’s eyes away from the “dominant story” made by one “plot” to “unique outcomes” of “un-narrated” and to rearrange it to an “alternative story”. Thereby it will release the client from the “dominant story” and make him/her live easily. But then distinguishing between truth and falsehood of a “narrative” will lose its meaning or get a totally different meaning. What is true would be what can cure the client. We cannot say which is true or false, the dominant story or the alternative story.

However, although this idea could be effective for a nervous client who persists in his/her view, it could lead also as a “narrative theory of history” to a dangerous revisionism of history, which I could not enter to discuss now. After I confirm that there is only a hairbreadth between truth and falsehood, I would like to seek a way to talk about truth and falsehood, without entering into a relativism between truth and falsehood, a relativism that it is enough if it heals, or that “a truth is a falsehood we need to live”, if we use words of Nietzsche.

#### **4. What the “narrative” therapy implies**

In regards to the life history of a person, not to place absolute value in a narrative solely from a perspective, not to settle only the dominant story, but to make it relative and to rewrite it to a story from an alternative perspective: that is the “rewriting therapy of narrative”. However, what happens, if life histories of plural persons entwine with each other? In such a case each has each perspective, however it is not the case that one of them will be dominant and others are alternative. We would say that each finds own perspective as dominant and the foreign perspective as alternative. As long as one places absolute value only in one’s own perspective, one can’t but repeat always misunderstanding and passing each other with others with other perspectives.

Whether one can accept other's perspective as an alternative story that could rewrite one's dominant story and exchange it with one's own in a situation: in that implies the possibility to open the closedness of one's own perspective to the other's one.

The Japanese sociologist UENO Chizuko(2001), based on the linguistic theory of post-structuralism, criticized the traditional concept of "subject", asserting that "a subject can come to being only by being subordinated to language, therefore neither an aggregate of subjects makes a society, nor subjects can exist outside of a society". Nevertheless, because "any reality is realized from a special perspective", UENO introduced instead of a pre-linguistic autonomous "subject" the concept of "agency" as a bearer of this special perspective who mediates from passivity of actions to activity, and concluded that "important is who and from which place gives utterance — the constructionism doesn't allow the transcendency of utterer by including the agency in the context". Then, however, even for the social constructionism it will be brought into question how stories of each agencies intertwine, overlap and adjust each other and how a reality will be constructed between plural agencies.

Here I would like to turn our attention towards a sample which applies a narrative theory to medical ethics. MIYASAKA(2005) raises as three methods for medical ethics "principle", "procedure" and "narrative", and says that "replacing theory of principle with context of procedure of medical staffs was the theory of procedure, whereas replacing it with context of patients' lives is the narratology (theory of narrative)." As said at the beginning of my speech, the importance of listening to patients' narratives is emphasized in various fields, but important in medical scenes is not always to accept every patients' narratives. It is not so simple if we take it into consideration that plural persons participating in medical scenes give meaning to own's actions from each narrative. From the beginning the social constructionism has the idea that a reality doesn't exist as a sole objective, but is constructed among plural persons. The "patient-oriented medicine" has been expressed, by criticizing the "doctor-oriented medicine", by emphasizing "illness" lived by patients different from "disease" grasped by doctors and by listening to patients' narratives. However, it doesn't mean always listening solely to patients' narratives and following patients' opinions. As much as patients have "patients' narratives" from the viewpoint of patients, family of patients has "family's narratives" from the viewpoint of family, even medical staffs have "medical staffs' narrative" from the

viewpoint of medical staffs. Thus MIYASAKA says that “narratology promotes making relative of viewpoints by that it is possible for a doctor and a patient to have a different valuation”. Further by asserting that “it could be effective to think about an ethical problem of medicine that narratives of every participants co-exist and that an ethical problem occurs as their disharmony”, he emphasizes the importance of “dialogue” between participants with their narratives from different perspectives.

This is related to the problem of determination of terminal care that has been often discussed recently in Japan. How can the narrative of a patient from the perspective of “the first person”, the narrative of his/her family or friends from the perspective of “the second person”, and the narrative of medical staffs from the perspective of “the third person” be adjusted and reach to a mutual agreement through dialogue? That is the problem here. In my paper (2007) I thought that we should set our goal, ideally to say, not in giving priority to one among them, but in seeking a point of agreement among those perspectives. There should be a question of narrative, perspective and alternative, too.

## **Concluding words**

As the German psychiatrist W. Blankenburg (1991) in his paper “pespectivity and delusion” said, one way of characterizing psychosis lies in adhering to one perspective, and in being not able to take another, alternative perspective. Whereas a person with a normal state can grasp the same thing not only with one aspect but also with another aspect, and understand a process of same events not only with one story but also with another story, “patients with mental disorders lack the ability to exchange the perspective”. A normal person can exchange, compare, antagonize or integrate one’s own perspective with the other’s one. Just in such a place we can talk about truth and falsehood intersubjectively, namely beyond truth and falsehood for a perspective. I mentioned already a “lag” between the narrator’s perspective and the listener’s one. But also in order to grasp the “lag” as “lag” we need an ability of exchanging perspectives. We adjust the “lag” through dialogue and communication with others. There is a place of intersubjective constitution of the world, where we should make clear about the “truth and falsehood of narrative”.

## Chapter 12

# TOWARDS A PHENOMENOLOGICAL APPROACH OF THE PROBLEM OF ORGAN TRANSPLANT AFTER BRAIN DEATH<sup>1</sup>

### Introduction

The Organ Transplant Act, which was established in 1997 after a long controversy, opened a possibility of organ transplant after brain death in Japan. This Act was revised in July 2009 and enforced in July 2010.

Concerning this Organ Transplant Act in Japan before the revision in 2009 I wrote in my paper as follows: “I may appreciate the fundamental idea that organ transplant after brain death would be only legitimate if an expression in paper of the patient’ will of organ donation after brain death and an agreement of the family with it are presupposed and medical conditions of the legal judgment about brain death is cleared. As an attitude of medicine following Japanese culture I find it not bad that only on the ground of patient’s will (the first person) and of family’s agreement (the second person) the medical legal judgment of brain death (the third person) should be performed”<sup>2</sup>.

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<sup>1</sup> The original Japanese version of this paper was published in *Machikaneyama-Ronso*, No.44, Philosophy, 2010 December. This arranged English paper was read at the 4<sup>th</sup> International Conference of PEACE (Phenomenology for East Asian CirclE), December 9-13, 2010, National Sun Yat-sen University, Kaohsiung, Taiwan. The Conference topic was “Border-Crossing”. The former speaker of my speech, Prof. Lester Embree (Florida Atlantic University) gave his speech “Some Phenomenology of not Retiring” in connection with his retirement at the university, whereas I gave my speech in connection with death as “Border-Crossing”. When we, or I, cross the border of life and death, who does or can decide it, whether I’ve already crossed the border or not? Medical doctor, I myself, or my family such as my wife or my daughters?

<sup>2</sup> “Caring of Life and Death — from Phenomenological Anthropology of Caring —” in: *Philosophy*(edited. by

However, as said, this Act was revised in 2009 and the revised Act was enforced since last July. The most important point of revision is that organ transplant after brain death would be legitimate, even if the patient's will is unknown, only if the family does agree with organ donation after brain death. It should destroy the condition of patient's will (the first person) in the fundamental idea that I appreciated ever. In this presentation, I would like to try to take this change and it's new situation into consideration. Through this discussion in this presentation I am going to prepare a phenomenological approach to the problem of organ transplant after brain death.

## 1. The problem of the first person

Scarcely a month has passed after the revised Organ Transplant Act was enforced, according which judgment of brain death and organ donation are legitimate only with an agreement of family, on the 9<sup>th</sup> August a young man in his twenties was judged as brain death and each harvested organs from him was transplanted in several medical institutions. Until today (March 2011) organ transplant after brain death has been performed in 18 cases<sup>3</sup> for these four months according to the revised Act, whereas we had 86 cases for 13 years since the establishment of the Act before revision, i.e. about 7 cases for each year.

At the first case the Japan Organ Transplant Network (JOTNW) that controls all organ transplants in Japan explained that the patient didn't express his will in paper, and that the family agreed with judgment of brain death, because he said formerly: "In case of an emergency I may donate my organs". But, as to how he expressed his will of donation, the Network gave only a comment: "While we in family were looking at a TV program about organ transplant, he expressed orally his will of organ donation, therefore the family estimated his will". The Network didn't announce as to details of the time etc. of conversation, because it could not get any understanding of the family for publishing it.

Although the time of the conversation is important too (How about it, if it was

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The Philosophical Association of Japan), No.58, 2007.4.1.

<sup>3</sup> This is the amount up to the day of the conference in Taiwan, whereas it has increased to 36 by now when I'm correcting this paper in March 2011.

10 years ago?), there are other questions. When is the “case of emergency”? Is it after death (after stop of heartbeat) or does it include after brain death (during heartbeat)? Is the state of brain death included in the “case of emergency” just as in this case? Was his oral expression based on understanding of such a distinction? Was the decision of the family based on recognition of his understanding about it?

However, such questions are nothing but tied to the framework of the old Act where an expression in paper of patient’s will was a necessary condition. As long as an expression of patient’s will is asked, it matters whether its content is 1) donation after brain death, 2) donation after stop of heartbeat, or 3) no donation. Differently the changed point of the revised Act of organ transplant consists in that not only when there is an expression of donation, but also when there is no expression of patient’s will, whether to donate or not to donate, only if there is an agreement of family, an organ transplant after brain death is legitimate, therefore that an expression of patient’s will is not necessary, whether orally or written.

Since even family’s supposition of patient’s will is not necessary, even a confirmation of his having said that “In case of an emergency I may donate my organs”, as above mentioned, is really not necessary. Even if his will is totally unknown, it is enough only if the total will of family in paper agrees with judgment of brain death and organ transplant: that is the point of the revised Act. Of course, if we can confirm that the patient expressed even orally a will of organ donation after brain death, family’s feeling could take a step forward easily to the direction that they want to respect patient’s will. The point of the revised Act is that only the agreement of the total will of family make it legitimate even if patient’s will is unknown. Just in above mentioned second and third cases it was the case. The reason why the family decided to donate when patient’s will was unknown was as follows: “If there is no help, I’m glad only when a part of body is alive. I hope that vigorous parts would be helpful for people”, “I would like to make a part of body useful for somebody. I’m glad when a part of body lives somewhere”. I cannot help saying that it is an agreement of the total will of family that doesn’t concern the patient’s will.

However, it is already asked whether this point of revised Act, “It doesn’t matter if patient’s will is unknown”, would go against the “fundamental idea” (the second article that is not changed after revision). This “fundamental idea” says that “the will of organ donation for transplant that the dead person had before death must be

respected". It is certainly true that in the revised Act both wills to donate and not to donate are respected, but when a person who expressed nothing about her/his will comes to donate with an agreement of family, does it mean that we respect patient's will? The second clause of the same article says that "organ donation for transplant must be voluntary". But, when patient's will is unknown, can we call this organ donation "voluntary"? Further, the third clause of the same article says that "organs for transplant are donated based on humanistic spirit". But, if patient's will is unknown, can we call it "based on humanistic spirit"? Although it must be said about patient's "humanistic spirit", I cannot help saying that it was transformed to family's "humanistic spirit" to "make organs useful for somebody".

## 2. The problem of the second person

This "fundamental idea" has a history. Namely, the report of the special research committee for organ transplant after brain death before the conclusion of the old Organ Transplant Act in 1997 ended with opinions of both sides, pro and contra. In the situation where one cannot insist that everybody agrees with considering brain death as death of a person, in order to open a way for people who may donate organs by considering brain death as person's death, the concluded Act made it legitimate to donate organs after brain death, by the thought of the right for "self-determination" that was influential on the background of those days.

However, even the old Act didn't consist only of the right for "self-determination". Because the conditions for organ transplant after brain death were not only an expression in paper of patient's will, but also an agreement with it by family. Even if there is the former condition, if there is not the latter condition, the organ donation becomes illegitimate, then the right for "self-determination" in a strong sense will be violated. According to the guideline for performing the Organ Transplant Act, the range of "family" covers in principle "one's spouse, children, parents, grandchildren, grandparents and relatives living together", and "the chief mourner should collect the total will of the family". If the chief mourner cannot collect the total will, organ donation after brain death becomes illegitimate. In this point the revised Act has no change. In the old Act it is necessary to full both conditions, not only the right for

“self-determination” of the patient but also the agreement with it by family, whereas in the revised Act, the former condition became not necessary and organ transplant after brain death became legitimate as far as family agrees.

This change made us examine the gravity of family’s decision in a totally new light. Please imagine: “Even if your loved person (e.g. your daughter/son) lies because of a heavily damage at her/his brain, you and your family is shocked. In addition, the patient is linked to an artificial respirator, although she/he has a pulse, her/his body is warm and sweats. Nevertheless the doctor says that her/his brain is already dead and she/he will reach soon to stop the heartbeat, and that there is no help, but there remains a way of organ donation”. In such a situation, under the old Act, organ transplant after brain death was only legitimate with the first condition, i.e. an expression in paper of patient’s will. If there is such an expression, it would push the family to a decision of respecting patient’s will and to a proposal of donation. In contrast with it, under the revised Act, even the patient’s will is unknown, therefore the family doesn’t think of a proposal of donation, medical staffs will approach the family by considering the patient as a candidate of organ transplant after brain death, and only if the family agrees with it, they can advance from the judgment of brain death to organ transplant. If the family will donate organs, there remains no enough time. In such a situation the family is demanded to make a decision. Does a decision in such a situation leave no regret, in case of which decision they made? It is no exaggeration to say that the gravity of family’s decision became of a totally different nature.

I would like to add one more thing to the problem of family, i.e. the addition of another point to the Act: “an expression of will about prior donation to a family member”. Also as to this it is pointed out that it would go against the “fundamental idea”: namely, “The organ transplant must be performed appropriately to a person who needs a transplant”, and, “The chance of getting organ transplant for a person who needs it must be so considered as to be distributed fairly”. Based on this “fundamental idea”, the Japan Organ Transplant Network make a waiting list of recipients’ candidates, then prior donation to a family member will be performed as a break of this fair rule. Besides, the family is restricted to “one’s spouse, children and parents”. The agreement for organ transplant after brain death in prior donation to a family member is also made by the family (and the range of both sides is subtly different). The idea that the so to speak ownership of corpse or organs belongs to

her/his family is more estimated than the fair right of chances for organ transplant. It is said that this revision of prior donation to a family member increased the number of people who express their will of donation. But it seems to me that the revised Act has strangely changed the problem of family from taking care of dying family member to asserting ownership of organs of family member.

### **3. The problem of the first person seen from the outside**

About such a situation that organ transplant after brain death become legitimate even without patient's will only with an agreement by the family, mass media reported often very schematically that "brain death became uniformly person's death" by the revised Act. These reports were not exact, but caused a misunderstanding.

Although the proposers of the revised Act said that they didn't insist that "brain death is uniformly person's death", their reason for it was as follows: "If the patient expressed her/his will not to donate organs, or also if her/his family doesn't agree with donation, neither the judgment of brain death nor the organ donation is not forced, therefore the veto power of both of the patient and her/his family is recognized". Certainly by emphasizing this point, in the "partly revision of guideline for applying the Organ Transplant Act" it is clearly expressed as follows: "To the patient who expressed her/his will not to donate organs or not to follow the judgment of brain death a legal judgment of brain death should not be performed". It is written clearly that to the patient who expressed her/his will of refusal neither judgment of brain death nor organ harvest would not be performed.

But it was not without reason that the mass media persisted in their expression that "brain death is uniformly person's death". Their point was as follows: "Whereas the old Act permitted 'brain death as person's death' only under two conditions (patient's expression in paper of her/his will and agreement of her/his family), the revised Act took off at least the first condition (the important requirement of patient's right of self-determination related with the "fundamental idea"). Since the veto power is allowed, we can't say that the revised Act abolished totally the first condition. Comparing with that in the old Act the first condition was only the case where the patient expressed her/his will to donate organs, in the revised Act the case where the

patient didn't express any will was added, consequently the case of no expression of patient's will become to be treated as same as the case with an expression in paper of patient's will. What the mass media wanted to insist can be probably said in other words such as "brain death is in principle a person's death". It means: By excluding the case with an expression of no donation as an exception, brain death is in principle considered as person's death.

It is viewed often as a conversion from *opt in (contract in)* as a system of *agreement expression* to *opt out (contract out)* as a system of *refusal expression*. Namely in the system of *opt in* only people who expressed an agreement become a candidate of organ transplant after brain death, whereas in the system of *opt out* only people who expressed a refusal is excluded from a candidate, i.e., except people who expressed a refusal all the others become a candidate. Shortly to say where the difference is, people who expressed nothing of their will would be treated differently. Namely, in the system of *opt in* they are excluded from a candidate, consequently they are treated as same as people who expressed a refusal will, whereas in the system of *opt out* they are put into candidate, so long as they expressed no refusal will, consequently they are treated as same as people who expressed a donation will. Before the revision, people carrying a donor card were no more than ten percent of Japanese population and people putting a circle around the number of "no donation" was a very few. People carrying no donor card in 90 percent didn't become a candidate from the beginning. On the contrary in the revised Act, except a small handful people who expressed a refusal in donor cards and a similar handful people who expressed a refusal orally all the other people would become a candidate. It was a great change of policy to increase the number of donor candidates.

In the system of *opt in* no donation is a principle (so to say "default") and people expressing donation are treated as an exception and become a candidate for donation, whereas in the system of *opt out* a donation is a principle ("default") and people expressing refusal of donation are treated as an exception and excluded from candidates for donation. Shortly it was a change from the old Act where no donation was a principle to the revised Act where a donation is a principle. Further to say in other words, because formerly organs were in principle patient's possession, only people who renounced particularly the ownership and expressed a will of donation are treated exceptionally and become a donor. On the contrary, because now organs

are in principle no patient's possession and so to say a common property, only people who insist particularly the ownership and express a will of no donation are treated exceptionally and become no donor.

To tell the truth, with this revision of the Organ Transplant Act a conversion from the thought "Organs are in principle patient's possession" to the thought "Organs are in principle common property" was done. Although we think that the latter new idea is so unfamiliar that many people in Japan feel incongruity, if then we are asked whether the former idea is so familiar and natural that we can feel sympathy, we feel hesitation about whether I should affirm it. There is a logic of "self-determination", "self-disposal" and "self-responsibility", from someone attempting suicide, a young man with tattoo, a heavy smoker, a sex worker, to someone who seeks to buy a kidney, because of poverty who says often as follows: "Because my body (including organs) is my own possession, how to dispose of it is my own business", "Since I will take responsibility for what I did, no others have right to meddle in my affairs", etc. We are somewhat repulsed by this logic and feel the following idea also persuasive for us: "My body is not my possession that I got by my work, but a gift from parents, God, or Heaven", "It is a gift that we inherited with DNA from the three thousand and eight hundred million years history of life, not my possession". It can become the ground from which another logic arises as follows: "Although my body is my possession, as long as I am alive, I don't care about that it becomes family's possession after my death". However, I would like to seek another thought different from the logic of possession about body and organs.

#### 4. The problem of the third person

The inexact schema of mass media "Brain death is uniformly person's death" included another misunderstanding as to the relationship between judgment of brain death and organ transplant. An impression was extended that in the old Act a judgment of brain death will be done only under the precondition of organ transplant, whereas in the revised Act "brain death is person's death" without the precondition of organ transplant. But there was not no reason for such an impression.

One important point of the revision of the Organ Transplant Act lies in the

second clause of article six that states “definition of brain death”. In the old Act it is stated: “a body of brain dead person” means “the body of the person from whose body organs would be harvested for the use of transplant and who has been judged that the function of the whole brain including the brain stem has irreversibly stopped”. But in the revised Act, since the underlined part of the sentence was deleted, “a body of brain dead person” means plainly “the body of the person who has been judged that the function of the whole brain including the brain stem has irreversibly stopped”. Formerly the definition of “brain death” has the condition related to the person “from whose body organs would be harvested for the use of transplant”, therefore it has to fill the two conditions, i.e. an expression in paper of the patient’s will and an agreement of family, moreover the third condition, i.e. a legal judgment for brain death that “the function of the whole brain including the brain stem has irreversibly stopped”. Consequently, if first two conditions are not filled, the judgment for brain death would not be done from the very beginning. The deletion of the above-mentioned part in the revision seems to allow an interpretation as if a judgment for brain death would be done without to fill the two conditions, consequently only if the result of the judgment would show brain death, it would mean person’s death.

In this point, the proposers of revised Act explained: “Because this Act is persistently the Organ Transplant Act which defines conditions making legitimate an organ transplant and is put into force within the frame of organ transplant, a judgment for brain death without a premise of organ transplant would be never done”. And, as said above, “To the patient who expressed her/his will not to donate organs or not to follow the judgment of brain death, a legal judgment of brain death should not be performed”. Also that the condition for organ transplant (the first clause of article six) and the condition for judgment of brain death are separated (although this separation follows the description of the old Act), seems to leave a possibility of the alternative to judge brain death without organ transplant by separating both conditions.

Even if the possibility of judgment of brain death without the premise of organ transplant is denied legally in the above-mentioned guideline, the second clause of article six is written, as if “a body of brain dead person” could be medically defined as “the body of the person who has been judged that the function of the whole brain including the brain stem has irreversibly stopped” and a judgment for brain death would be medically performed. Then, I would like to ask again: Can we medically

(objectively) declare that brain death is person's death?

If we look back the history, the first heart transplant in the world was done by doctor Bernard in the Republic of South Africa 1967. Since it was a transplant after stopping heartbeat, the recipient died after only 18 days alive. After that people discussed whether a heart could be harvested before stopping heartbeat to transplant it freshly or in which point in time a heart may be harvested. In the next year 1968 the special committee for brain death of the medical faculty of Harvard University in U.S.A. defined death of the whole brain (in the expression of the report of the committee "comma dépassé") as a new criteria for death. Responding to this, the Uniform Determination of Death Act in 1981 declared: "[Judgment of death] A person who fell into 1) irreversible stop of circulation and respiration, or 2) irreversible stop of the whole brain including the brain stem is dead. The judgment of death must be performed according to the approved medical criteria". This is an Act that considers brain death as person's death besides cardiac death. This made heart transplant after brain death legitimate, promoted by the development of immune restraining medicines, so that in U.S.A. since 1990 more than 2,000 heart transplant were performed every year. Compared with such a situation in U.S.A., in Japan since the Act for Organ Transplant was enforced in 1997, and from 1999 up to 2010 only 86 organ transplants after brain death in all, among them 70 heart transplants, were performed. There is no comparison between the two countries, so we notice that U.S.A. is an greatly advanced country with organ transplants.

Nevertheless in such an advanced country in organ transplants, U.S.A., in these years a little different movement appeared, namely controversies are very active about the definition of death that has already come to a social consent. On such a background, *CONTROVERSIES IN THE DETERMINATION OF DEATH, A White Paper of the President's Council on Bioethics* (Washington DC, December 2008) was published. In this report it is recognized that "judging person's death with whole brain death became difficult" from cases such as "long-term brain death", and "come back alive from brain death". The report pointed out at the beginning that the term "brain death" is problematic, that in the controversies about whether "brain death is person's death" the term including the word "death" let have a prejudice, so that they propose here the term "total brain failure" or more clearly "irreversible total brain failure".

Moreover, the report paid attention to the method of “Controlled donation after cardiac death”. In this method the artificial respirator of a patient retaining a little function of a heavily damaged brain is removed in accordance with the will of patient or family. After confirmed the stop of heartbeat and waited two till five minutes, the blood circulation in the brain stops and the cells of brain would perish soon. Immediately the waiting team for transplant harvests organs from the patient. In a word, the patient who doesn't arrive at brain death would be brought to the stop of heartbeat and to be harvested immediately. This method, named Pittsburgh Method, was established in 1992, and performed in 793 cases in 2007. The report said that it will be also supported by people who don't consider brain death as person's death, so that with the help of UNOS (United Network for Organ Sharing) it is now rapidly spread in all over United States.

This *White Paper* shows that the U.S.A where brain death was very early legally defined as person's death and people pushed forward with organ transplants after brain death have nowadays turned their attention to the problem of regarding brain death as person's death, so that they are now seeking a way to make heart transplant possible not after brain death but after cardiac death.

## In Conclusion

My paper mentioned at the beginning of this presentation was written on the background of controversies about the terminal care in Japan when the Japanese Ministry of Health, Labor and Welfare was wanting public comments to the “guideline concerning medicine at the terminal stage (a tentative proposal)”. There I wrote also about the terminal care as follows: “Therefore people think in Japan that the three standpoints, such as the first person of advance directives of the patient, the second person of consent by family etc, and the third person of judgment by medical staffs, need to keep a communication and build a mutual agreement through dialogue. I find it not bad as a situation in Japan, so that the idea doesn't face a bad direction.”<sup>4</sup>

After that, by adding a small revision to the tentative proposal, the Ministry

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<sup>4</sup> See my paper above mentioned at the footnote 2 of this paper.

announced the “guideline concerning the decision process at the terminal stage” on May 2007. We can say that concerning the policy of the terminal medicine and caring, the posture of seeking a mutual agreement through communication or dialogue of the three at least as an idea. It would be better, if we could find at least a similar posture also in the problem of organ transplant after brain death.

In the revised Organ Transplant Act, compared with the guideline concerning the terminal care, the viewpoint of the third person of medical judgment got more weight, the viewpoint of the second person was turned rather to the decision about whether to agree brain death and organ transplant than to the caring for the patient in “brain death” state, and the viewpoint of the first person, especially about most people not expressing the will of donation, seemed to be forcibly interpreted to the will to donation. Although there are already some bibliographies about the second person viewpoint of the problem of organ transplant after brain death<sup>5</sup>, there is seldom enough considered about the first person viewpoint. Keeping watch these three perspectives, a phenomenological approach to this relationship would be now expected.

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<sup>5</sup> E.g. Masahiro Morioka, *The Person in Brain Death — From the Perspective of Life-Science*, 1989; Kunio Yanagida, *Gisei (Sacrifice) — My Son: Eleven Days in Brain Death*, 1995.

## Chapter 13

# A COMPARATIVE INQUIRY ON “ADVANCE DECISION” IN JAPAN, GERMANY AND UK

### **Introduction**

What can we do as a family member, if a loved one is reaching to the end of life? My interest in the problem of caring began when I lost my father in law because of pancreas cancer 15 years ago. His spouse, my mother in law, passed away in April last year, after suffering dementia, Alzheimer’s disease, for 9 years and living in a group home close to our home. In this case I faced the same question in a different way. Her symptoms became worse and worse, and although she took to medication delay the progress of disease. Since about two years she rapidly lost her physical strength and began to eat and drink less. The head of the group home said once that she seems to have reached the end of her life, but that the group home doesn’t have any system of end-of-life-care, and asked us to move her to a hospital for the elderly or geriatric ward. But we, my wife and I, refused this demand because a hospital is a medical institution and an entering there means that people begin a medical treatment (artificial hydration and nutrition), which we don’t want. We continued to negotiate with the head of the home by asserting that if necessary we will come to stay every night, and that we want to accompany her at the end of her life at the same place she spent the last years. With help of our home doctor we persuaded the head, got an understanding and successfully managed to accompany her to the end of her life at this group home also with help of visiting nurses. A week before her passing away the visiting nurse gave training seminars for accompanying her to the end of her life to caring staffs, the head of group home and my wife. At last she passed away by being grasped by my wife and my younger daughter. The home doctor arrived two hours

later wrote the death certificate. The cause of death was “senility or natural death”.

During such a personal incident there was a movement to legislate death with dignity in Japan which I was interested in as a problem that I couldn't feel that it was no concern of mine. The following is my report of what I have investigated and considered within such a situation.

## **1. Background of legislation of death with dignity in Japan**

Recently, a controversy about the legislation of “death with dignity” broke out again in Japan. The trigger for it was the announcement in March 2006 that a surgeon in Imizu municipal hospital of Toyama prefecture removed artificial respirators of seven patients at terminal stage. In next years it caused a strong controversy. Problems that appeared were:

1. In most of those cases the wishes of patients were not confirmed.
2. The surgeon as well as patients' families were consented not explicitly in papers, but in an implied mutual understanding.
3. The surgeon is believed to make the final decision alone without any consultation with other medical staff.
4. People raised one's voice that hospitals or the government should make a rule or a guideline.

After all the surgeon was not prosecuted because the families didn't accused him.

But because of this controversy from 2007 to 2012 there appeared various kinds of guidelines from different senders by starting with “Guideline on process of decision making in terminal medicine” by the Ministry of Health, Labor and Welfare” (May 2007). If I may focus solely on this guideline, it says: “A beginning or not-beginning of medical treatments on the terminal care, a change or a canceling of medical treatments, and so on should be deliberately judged based on medical validity and appropriateness by medical-caring team composed from medical professionals”. In short, it shows an attitude that only if they go through a right process of decision making, there could be a withholding or withdrawal as alternatives. Although people discussed with an assumption mainly with artificial respirators, soon the problem of artificial nutrition has been discussed. In 2012 the association of gerontological

medicine announced "Guideline on process of decision making of elderly caring — centering on an introduction of artificial hydration and nutrition"(June 2012), which showed an attitude: "If people examine a withdrawal and reducing of artificial hydration and nutrition and expect it better or more benefit for patient's life than continuing a preceding treatment, there would be a choice of withdrawal and reducing as alternatives".

In such a situation, the popular interest in death with dignity grew up and discourses of "natural death", "peaceful death" and "satisfied death" were spread. On the background of such a popular interest there appeared the movement of "legislation of death with dignity". The "Japan Society for Death with Dignity" submitted a petition for legislation of death with dignity to the both Houses. In 2011 the league of interested member of the Diet (Parliament) was build and announced the "Bill on a respect of patient's will at the terminal medicine". In spite of the naming of the Bill, it's sentence says "withdrawal of life-prolonging treatments and it's immunity of doctors", therefore we must characterize it as aiming of legislation of death with dignity.

The Bill says further: "It is presupposed that the patient expresses his/her will of wishing a withdrawal etc. of life-prolonging treatments in papers or a method provided by the Ministry of Health, Labor and Welfare". A question remains however whether the "Declaration of Death with Dignity (Living Will)" of the Japan Society for Dying with Dignity supporting this Bill is appropriate or not. This "Declaration" was revised in 2011, but it's fundamental stance was not changed. It is namely based on the right of self determination of patient, has therefore the form of "declaration", doesn't presuppose any communication with family or proxy, and would be registered by post. As it doesn't presuppose any communication with a doctor, there would be a possibility that the patient misunderstands the medical terms used in the "declaration" such as "life-prolonging treatments", "palliative care" or "persistent vegetative state". It focuses solely on the declaration of declining life-prolonging treatments, gives only one choice in the form of signing on the fixed format. The legislation of death with dignity in Japan seems to respect patient's will by situating such a document legally and to exempt the doctor performing the withholding or withdrawing of life-prolonging treatments from taking responsibility.

On the other hand, there is a countermovement centered round the Japan Federation of Bar Associations. They say that the problem of withdrawing of life-prolonging treatments should be situated within the context of fulfillment of terminal care including hospice and palliative care and of the right of patients to get a medicine with good quality, without which it should not be decided separately. There is also another countermovement centered round associations for disabled persons. They say that there are plenty of disabled persons surviving with artificial respirator or artificial hydration and nutrition which are apt to be taken as life-prolonging treatments, and that if death with dignity is legislated the definition of terminal period could be spread to threaten the life of persons surviving with such helping methods. These counter opinions would be understandable.

## **2. Recent trends regarding legislation of death with dignity in Japan**

I would like to summarize trends in 2014 in the above-mentioned background.

A Report of bioethics committee of the Japan Medical Association, "Bioethics on medicine today - especially on terminal medicine, gene diagnose and gene therapy", and another report of committee for opinion poll in the Ministry of Health, Labor and Welfare, "Report of opinion poll on medicine for terminal stage of life", were released both in March 2014. In the former pros and contras on the legislation of death with dignity are introduced and in the latter the situation of spread of the above-mentioned guideline of the Ministry to clinical scenes is reported.

The former mentions as pros opinions: The legislation is necessary, first, to respect patient's will and to protect the right of patients to get appropriate medicine including life-prolonging treatments; secondly, to guarantee the smooth and appropriate execution of medicine by protecting the legal constancy of medical staffs engaged with terminal medicine; thirdly, to secure the popular confidence concerning the appropriate execution of terminal medicine.

The same mentions as contras opinions: It is unnecessary, first, because it would cause an interpretation in the medical scenes that actions except legally provided ones are not allowed so that the right of patients is consequently restricted; secondly, because before enacting a law only directed to the withholding or withdrawing of

life-prolonging treatments and guaranteeing the so called "right to dying" the first question is to guarantee the so called "right to living" in order for patients to get appropriate medicine; thirdly, because we should make further efforts to fix the system of terminal medicine respecting the will of patients by Living Will and so on and to execute effectively the guideline of the Ministry or the Japan Medical Association.

The latter report points out the following results of opinion poll: First, although there are many people agreeing with making papers to express one's will in advance, there are only few people who have made such a paper already; secondly, there are more people thinking it unnecessary to legislate the decision of medical plans according to a paper than people thinking it necessary; thirdly, there are many people agreeing with advance selection of a proxy from family or others who can decide substitutively in preparing the case when people can't judge by themselves; there are not so many people considering the above-mentioned guideline, rather not few medical staffs who don't know it at all; fourthly, there are only a few people thinking it necessary that the definition of terminal period and the standard for decision to withdraw life-prolonging treatments should be fixed in details, whereas there are many people thinking it enough for medical staffs to examine and decide medical plans in details with patient and his/her family if there is only a rough criterion.

Among such a situation of controversy with pros and contras on legislation of death with dignity in Japan, I had an opportunity to stay in Germany. Based on information I got there I would like to confirm the situation of legislation of death with dignity enacted in Germany and to compare it with the situation in Japan.

Incidentally before comparing with situation in abroad especially in Europe I need to point out that people in Japan distinguish between "euthanasia" and "death with dignity", whereas there are countries where people don't distinguish between both. In Japan people call doctor's giving deadly medication to patient according to his/her will (positive euthanasia) as well as doctor's prescribing the same with leaving it to patient whether to take it or not (physician assisted suicide: PAS) "euthanasia", and also the above-mentioned guideline of the Ministry leaves both out of consideration, saying that "an active euthanasia with purpose to shorten the life is not an object of this guideline", because both of them could be understood as "murder (including aiding and abetting a suicide)" in the criminal law. By distinguishing from the both

people in Japan call “withholding and withdrawing of life-prolonging treatments” (negative euthanasia) “death with dignity”, whereas in Netherlands or Oregon State in U.S. people call the positive euthanasia and PAS also “death with dignity”. In the following I would like to focus only on “death with dignity” as “withholding or withdrawing of life-prolonging treatments”.

### **3. Legislation of “Advance Directives” in Germany**

Already in 2009 the “Advance Directives (Patientenverfügung) was legislated. The document “Advance Directives — Suffering, Diseases and Dying — In Case I lost my decision capacity, how I can direct which treatment is executed?” in 44 pages is to be downloaded from web site of German Ministry of Justice and Consumer Protection. It is composed from 1. What are advance directives, 2. Components of formulae of advance directives, 3. Two samples (two extreme cases). People should not select the choices with checking, but describe or explain. Characteristics could be summarized in following:

Differently from the above-mentioned “Declaration of Dying with Dignity”, we can (not must) not only express our will of “withholding or withdrawing of life-prolonging treatments”, but also express our will of which treatments we wish in case I lost my decision-making capacity. The advance directives don’t end with filling in the paper, but must be interpreted substitutively by others. For this purpose the necessity of a proxy or an attorney is emphasized. The explanation by a doctor is also mentioned and the column for doctor’s signature is prepared. The term of validity and revision is considered. To say how it is spread in fact, e.g. in Heidelberg where I spent three months the year before last, “A letter of attorney”, “A letter of guardian” and “Advance directives” in a set are distributed at the bureau of conservatorship of the town hall.

The most important point is the substitutive interpretation by an attorney. Advance directives of patient is fundamentally considered as a tool for realizing the right of self determination, but as not settled only with self determination. Even if a patient has filled in advance directives, he/she cannot decide by him/herself in which point in time and how the advance directives should be executed. Even if the writing

of advance directives could namely be determined by him/herself, its execution could not be determined by him/herself. The text of advance directives needs an interpretation by others in the most important point in time. Unless the patient designates who does the interpretation, it doesn't work at all. In such a situation the designation of an attorney is important. Such context within which advance directives are situated should be taken into consideration.

The legislation of advance directives in Germany is executed in the form of revision of the existing Conservatorship Law (Betreuungsgesetz). This Law enacted in 1990 and enforced in 1992 is a drastic revision of the preceding Guardianship Law. The preceding system of pronouncement of deprivation and restriction of acting capacity, and of protection of action and obstacle intending an adult was abolished, and a system in civil law of supporting an adult with dysfunction of judgment has been unified into the Conservatorship Law. Its object is considered to include 1. Old psychiatric patient, 2. Patient with mental disorders, 3. Alcohol dependents, and 4. Mentally retarded person. By abolishing unfair discrimination against adult guarded persons and enriching an appropriate support system, the revised law intends to promote their social participation and integration to the society. In its base the idea of normalization and self determination was included.

The Conservator Law introduces a voluntary attorney different from a legal conservator. If the client gives the advance attorney right to a reliable person, he/she doesn't need any conservator. A conservator is ordered only if the client needs a support and can't expect any help of relatives, acquaintances or social service. The right of advance attorney is an alternative for selection of legal conservator and by designation of voluntary attorney he/she can protect against the intervention of state or law. Unless we designate any reliable voluntary attorney, we would leave any decision to the legal conservator selected by a court. Then we return to the document of "A letter of attorney" among the distributed papers of the town hall in Heidelberg. Unless we entrust any voluntary attorney, a legal conservator will come to intervention. Although we can propose or recommend a conservator, e.g. a reliable lawyer, because it is only a proposal, a court judges whether this conservator is allowed or not. If we have no proposal, or if our proposal is rejected, a conservator selected by a court will come to intervention. To propose a voluntary attorney we use the document of "A letter of guardian" among the distributed papers in Heidelberg.

The idea lying on the background of this system can be found already in the “Advance Directives — Midterm Report of the Council of German Parliament (Bundestag)—”(2004). It’s preface understood “dissolution of traditional family constitution” as the current situation in Germany, in the background of such a change of society it posed that such advance directives are meaningful as far as they determine in a paper what people could get a consent of opinions generally in those days, and presented a concrete bill in order to legislate patient’s advance directives. It presented not only rules of advance directives, but also tried to situate them in a wider context. It said namely: “The decisive point is to improve the attitude of accompanying serious patients and dying patients, and to enrich the palliative care and the hospice system. The controversy on advance directives by patients should be always situated within this context.” It said also: “The problem reaching further of accompanying dying patients including the enrichment of physical, mental, social and spiritual demands could not be captured with advance directives”. Although it confirms that the right of self determination is a fundamental human right on the one hand, advance directives should be situated among the total relationship of individual’s freedom, human welfare, duty of doctors and nurses, rights based on the patient’s right and medical effects. Another report of the same council “Human Dignity and Gene Information” said: “Everybody depends on support by others in order to assert and protect his/her right of personal freedom at many stages of his/her life (e.g. in infancy, in case of disease, or in old age)”. It confirmed that human being is “a free and dependent being”.

To summarize: The “Bill for death with dignity” in Japan focuses only on the withholding or withdrawing of life-prolonging treatments and comes from the guarantee of the so called “right to dying”. On the contrary, according to the advance directives in Germany we can write either of wishing or non-wishing of life-prolonging treatments, and assert not only the “right to dying” but also the “right to living”. Moreover they are situated among the “Conservator Law” with entrust of voluntary attorney and designation of legal guardian. This “Conservator Law” is a law guaranteeing the “right to living” in order for an adult having lost the judgement capacity to survive with support. The so called “right to dying” is situated among the “right to living”.

#### 4. Legislation of “Advance Decision” in UK

In September 2013 I've participated in the 11th international conference of “Death, Dying and Disposal — where theory meets practice”. Although the conference was full of schedules, I would like mention only information which I got at the a parallel session with theme “End-of-Life Care”, because I would like to focus on the legislation of advance directives in UK.

Some presentations of the session reported about activities of the association of “Compassion in Dying”. Before participation in this conference I was informed about the situation in UK only that there is a living will made by the “Voluntary Euthanasia Society England” which seems to have a legal binding force as a judicial precedent. With presentations about the association of “Compassion” I came to know that in the UK, the “End-of-Life Rights” are legislated under the “Mental Capacity Act” since 2007, two years earlier than in Germany, though the law, in effect, only applies to England and Wales, Scotland and North Ireland having different and separate legal systems.

Since the next year of the legislation 2008 some voluntary associations were born to let spread the idea of the “End-of-Life Rights”, answer questions and support people having questions, one of them is this “Compassion in Dying”. This association keeps in step with another association “Dignity in Dying”, but tries to keep a distance from this association, because the latter intends to expand the “End-of-Life Rights” to “assisted dying” (assisted suicide), whereas the former doesn't intend to have nothing with the campaign to legislate the assistance of dying. With the above-mentioned distinction the former intends to stay in “death with dignity (withholding or withdrawing of life-prolonging treatments”, whereas the latter intends to step in “euthanasia (physician assisted suicide)”.

According to the assertion of the “Compassion” we can refuse treatments as the “End-of-Life Rights” even if it caused death as result. For this purpose we need not to justify our decision, but need to show that we have mental capacity. If a patient is an adult with mental capacity, he/she may decide to refuse a treatment in advance, and this decision has a binding force. If he/she loses mental capacity to decide and to communicate (e.g. in case of heavy dementia or coma), the advance decision becomes valid. Methods that a patient can take in order to let respect own will are: 1. making

“Advance Decision” (corresponding “Advance Directives” in Germany), 2. designating “Lasting Power of Attorney” (corresponding “Voluntary Attorney” in Germany). There are formulae including both points to be filled.

The important points to make “Advance Decision” are: 1. to be written correctly, 2. to be consulted with a doctor, 3. to be consulted with loved ones (not written as family), 4. to be updated to a newest one, 5. to be applied to a right situation. There are treatments we can refuse and those we can’t, e.g. cardiopulmonary resuscitation (CPR), artificial respirator, artificial hydration and nutrition, and medication of antibiotics could be refused, whereas natural meal and water (no treatment), pain relief, care for comfort (e.g. oral care), hygiene (e.g. bed-bath) could not. Important points on designation of “Lasting Power of Attorney” are: 1. The preceding system of the “Enduring Power of Attorney” in the “Mental Capacity Act” mainly purposed to manage the property is expanded to the support of decision making about health and welfare; 2. Unless the patient designates the attorney, medical staffs ask his/her family or relatives about treatments, but legally they need not to obey their opinions.

According to the assertion of the association “Compassion”, we can use “Advance Decision” and “Lasting Power of Attorney” for refusal of life-prolonging treatments, but not for request to end our life. To end medically the life of patient according to his/her demand is to assist dying and assisted suicide or voluntary euthanasia which is legally not permitted. The association says that they don’t intend to give information about method to end own life.

To summarize: I’ve introduced that in Germany advance directives have been legislated by incorporating them into the Conservator Law in June 2009. In UK, however two years earlier in 2007, the “Advance Decision” as “End-of-Life Rights” has been legislated under the “Mental Capacity Act”, namely in a similar way. And both are legislation in totally different way from the proposed legislation of solely “Bill for Dying with Dignity” in Japan.

## Conclusion

Among European countries there are on the one hand countries where euthanasia (positive euthanasia and/or physician assisted suicide) is legislated (or

allowed with a bar to illegality) such as three Benelux countries and the Switzerland, on the other hand there are countries where euthanasia is not allowed, but death with dignity (withholding or withdrawing of life-prolonging treatments) is already legislated, such as Germany and UK. But even in the latter countries not solely death with dignity is legislated, but it is legislated by incorporating the choose of death with dignity into the law guaranteeing that weak people having lost mental capacity can survive with dignity until to the end of life. Returning to the situation in Japan where we have no such a conservator law (although there is a system of conservator, it doesn't concern with the medical decision relating to life and death), the question remains whether it is necessary to legislate only death with dignity. Rather in the situation where the guideline of the Ministry functions to some extent, it is more important to let it spread and to expand an accumulation of decision making through the clinical content intending to enrich hospice, palliative care and comprehensive regional care, and to spread living will and advance directives with good quality. I think that my personal experience which I introduced at the beginning of this paper can contribute to one of such an accumulation.

## Chapter 14

# TOWARDS STUDIES OF NORDIC CARING — A DIFFERENT PHENOMENOLOGICAL APPROACH —<sup>1</sup>

### Preface

In nursing research, one should be interested in phenomenological research (JPN NURS RES, 2011a) as well as caring (JPN NURS RES, 2011b). Due to holding an interest in both these areas and participating in a collaborative project called 'Phenomenology of Caring', I have a further interest in 'Nordic Caring' as a contact point between phenomenology and caring. Therefore, for two years, I have been engaged in an interdisciplinary collaborative research titled 'A research into theoretical grounds and philosophical backgrounds of Nordic Caring based on field work'. The collaborators on this study are from fields such as philosophy, ethics, thanatology, nursing science, rehabilitation science, social welfare and cultural anthropology.

Our research of binding field work to a philosophical background is not a simple process, and as yet, we cannot gauge the complete results of the study. Nevertheless, I introduce our activity so far as a progress report and provide a different approach to 'phenomenological research' of 'caring'.

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<sup>1</sup> This is an English translation of my Japanese article published in: *The Japanese Journal of Nursing Research*, Vol.45, No.05, 2012 Aug-Sep., Special Feature: Nordic Caring for Nursing Research, pp.428-438.

## 1. Beginning of our Research

I am neither a nursing researcher nor a Nordic studies expert, but I conducted research in phenomenological philosophy (Hamauzu, 2007a). Furthermore, I have been engaged in establishing a platform for dialogue among researchers and between citizens and researchers in medicine, nursing, social welfare, etc., titled 'Anthropology of Caring' (Hamauzu, 2005; 2007c) and 'Clinical Philosophy of Caring' (Hamauzu, 2012a). For the last three years, owing to scientific grants-in-aid, I have been participating in collaborative research titled 'Foundation and Development of Phenomenology of Caring' and 'Concrete Development and Organization of Phenomenology of Caring' (Hamauzu, 2011). During these activities, I interacted with nursing researchers; however, my interest in Nordic caring emerged due to another encounter, which is explained below.

In 2007, I visited many facilities for elderly people and hospices or palliative care units in Shizuoka Prefecture as part of a collaborative research titled 'Ethics and Laws of Personal Assistance' (based on clinical psychology and human care). Based on this activity, in November 2007, I participated in the 'Study tour of visiting welfare service and feeling every day life in Nordic countries' (Hamauzu, 2008). I visited various facilities for human care in Nordic countries (primarily Sweden and Denmark) with other participants from medicine, nursing and caring and social welfare. These visits and interviews with staff members motivated me to consider the theme of 'Ethics and Laws of Personal Assistance', the issue of 'self-decisions' of the elderly and terminally ill and the paradoxical relationship between 'enrichment of caring' and 'suspension of medicine', among others. This is when I developed an interest in the foundational concepts of caring for the elderly in Nordic countries.

Regarding my phenomenological interests, I belong to the Phenomenological Association of Japan (PAJ), which in 2007 began an international scientific exchange with the following groups: the Nordic (NSP), Korean and Chinese Societies for Phenomenology (Sakakibara, 2007). In 2007, these groups each sent a researcher to conferences in each of their home countries. At the 2007 PAJ conference, Sara Heinämaa, president of the NSP, from Finland's Helsinki University, presented a speech (Heinämaa, 2008). At the 2008 conference, Marcia S. C. Schuback, a Swedish researcher from Sweden's Södertörn University College, made a presentation

(Schuback, 2009).

Meanwhile, we began the collaborative research on the 'Phenomenology of Caring'. Schuback's 2008 presentation topic, 'Immensity and A-subjectivity' about the 'possibilities of encountering the other' overlapped with my ongoing research. She was interested in my development from 'theory of others to theory of caring'. Our conversation at the reception after the conference provided me with information about a Swedish group also interested in 'phenomenology and caring', and Schuback introduced me to a core member of the group, Karin Dahlberg. In 2009, I had the opportunity to present 'Narrative and Perspective' at the NSP conference in Tampere, Finland (Hamauzu, 2009b), following which I travelled to Växjö, Sweden, to meet Dahlberg.

Karin Dahlberg is the leader of the Växjö research group and Guest Professor at the School of Health and Caring Sciences, Lifeworld Centre for Health, Care and Learning, Linnaeus University. In fact, she contributed to this issue of the periodical. My travel schedule allowed me to participate in an entire three-day event of related programmes in Växjö. The first programme was the inaugural meeting of the European Academy of Caring Science (EACS); the second was an education seminar for doctoral candidates on 'lifeworld-led-care: an existential point of view of well being'; and the third, a meeting for collaborative research between Bournemouth and Linnaeus Universities, titled 'Lifeworld-led-care and Education'. These programmes indicate a movement of caring science different from that of nursing science in the United States. Phenomenology is central to this movement, and this is extremely interesting for me.

Because the collaborative research 'Phenomenology of Caring' had begun in April 2009, the idea of collaborating with the Nordic researchers was very appealing. However, because the collaborating members on the 'Phenomenology of Caring' research are primarily centred on nursing science and not on Nordic caring (Sakakibara, 2011), it was difficult to incorporate this Nordic collaboration into that research.

Therefore, I interacted not only with researchers interested in nursing science but also with researchers interested in rehabilitation science, caring science, social welfare and so on. In April 2010, the collaborative research 'A research into theoretical grounds and philosophical backgrounds of Nordic Caring based on field work' began.

Because of this serendipitous background, I subtitled this article 'A Different Phenomenological Approach'.

The purpose of the research (quoted from the application) was as follows: 'Many researchers on welfare system on one hand and caring studies on the other have often visited the Nordic countries famous for their well-developed welfare system. Some of these researchers have reported on the concept of "normalization" and the leading values of the Swedish model, such as "freedom, equality, equal opportunities, peace, safety, security and fairness." Nevertheless, it is insufficient to clarify their theoretical grounds and philosophical backgrounds. To research these welfare systems, not through written literature but by fieldwork, i.e. investigating the operational realization and activation of these ideas, is expected in a super-aged Japan, where a theoretical foundation of welfare and caring is a pressing need'.

In this collaborative research, we visited various caring facilities (e.g. hospitals, hospices, facilities for the elderly and the handicapped and homes) and interviewed the care staff and clients. In addition, we visited Nordic researchers (of phenomenology and caring sciences) to exchange opinions. In our follow-up meetings, we reported the observations from our visits and conducted detailed discussions with co-researchers.

## **2. Development of Our Research**

We are in the final year of our collaborative research. During these three years, all members of our project have conducted fieldwork in Nordic countries and reported their findings. Furthermore, based on the members' reports about Nordic caring within each area of expertise, we held eleven discussions analyzing the results. One more meeting and a symposium have been planned for January and March 2013, respectively, to release the results of our research to the public. The following is a list of our meetings so far:

The first meeting at Osaka University in May 2010:

Shinji Hamauzu, 'Keynote speech — Going towards Nordic caring studies'

The second meeting at Shizuoka University in August 2010:

Taisei Yamamoto, 'Movement of Body and Genesis of Health — from a point of view of using bodily resources'

Nobuhiko Bishu, 'Transition of caring in Japan and the future from Nordic caring'

The third meeting at Kobegakuin University in January 2011:

Ryutaro Maeno, Shinji Hamauzu and Yasuuki Suzuki, 'Report of study in Nordic countries No. 1: United Kingdom, Sweden and Denmark'

Yutaka Nakagawa, 'Report of Study in Nordic Countries No. 2: Music therapy in Norway'

Teruko Takahashi, 'Interest in Nordic caring from nursing field'

Isao Nara, 'A philosophical investigation about caring from the standpoint of physiotherapist'

The fourth meeting at Osaka University in March 2011:

Eijiro Fukui, 'Anthropology, Others and Caring'

Shinji Hamauzu, 'What is Lifeworld?'

The fifth meeting and symposium, 'Nordic education and caring' at Nagoya University of Arts in July 2011:

Naoto Koike, 'The concept of Enlightenment in Grundtvig and Nordic democratic society'

Mitsuru Shimizu, 'Schools for life — from interaction with the Grundtvig movement'

Satoshi Nakazato, 'Nordic education and caring — Reality supporting the field'

The sixth meeting at Osaka University in October 2011:

Junko Stier, 'Nordic caring that a Japanese watched — From experience as a nurse in two countries'

Karin Dahlberg, 'Patient-centered-care as Lifeworld-led-care — From the point of view of Nordic caring'

The seventh meeting at Konan Women's University in December 2011:

Shinji Hamauzu, 'A short Report of Study Travel — Hospice and Palliative Care Unit in United Kingdom and Sweden'

Tsuyoshi Nakamura, 'A Hypothesis about theoretical basis of Caring in Sweden'

Eijiro Fukui, 'Caring and Personhood from the Theory of Donation'

Taisei Yamamoto, 'Psychophysiotherapy in the Mental Health & Basic Body

Awareness Therapy'

The eighth meeting at Seirei Christopher University in March 2012:

Yutaka Nakagawa, 'Development of Music Therapy in Norway and its Philosophical Grounds'

The ninth meeting at Shimane University in June 2012:

Hiromu Takenouchi, 'To Social Grounds and Philosophical Cornerstones of Nordic Caring — What the "Welfare" in Sweden questions'

Nobuhiko Bishu, 'Sense of Discomfort against Protective and Educational Care'

The tenth meeting and symposium, 'Re-inquiring Welfare — With the Clue of Understanding Human Being Supporting Nordic Caring' at Shizuoka Prefectural Hall of Industry and Economics in December 2012:

Yayoi Saito, 'Caring as a question — Thinking from Elderly Caring in Sweden'

Kanako Korenaga, 'Theory and Praxis of Education of Children with Disabilities — The View of Human Nature Supporting the Education of Children with Disabilities in Sweden'

Teruko Takahashi, 'Nursing and Welfare — Historical Transition and Tasks'

As seen above, the co-researchers each gave a presentation based on their fieldwork considering Nordic caring from their respective fields. As our research developed, we felt the necessity of researching Nordic education, which is bound to Nordic caring. Thus, we invited three researchers from education. By connecting fieldwork research with theoretical investigations and sharing research from each area of expertise, we have amassed discussions and considerations. Because the contents of each presentation can be published in other ways, I first address Junko Stier's speech, followed by Tomoko Hansson's (an official guide of Göteborg, a writer and translator who specializes in social welfare) lecture and finally, Karin Dahlberg's speech to introduce the following three articles.

I first met Junko Stier when I participated in the 'Study tour of visiting welfare service and feeling every day life in Nordic countries', for which she was the interpreter. She invited us to her home, and I had the opportunity to ask her about Swedish people's thoughts on issues such as euthanasia and terminal care (Hamauzu, 2008). We were fortunate to hear from a nurse who has worked in both Japan and Sweden,

and who is now an interpreter mainly in tours for medical professionals or caretakers.

The most important points from Junko's stories are as follows: First, in the national movement since the 19th century, solidarity and independence have had inherent linkages. Second, caring is helping someone towards becoming independent; it is also placing importance on self-decision and not interfering extensively. Third, due to medicine and caring focused on patients, the treatment period is short. The average hospital stay is about 6 days in Sweden, whereas it is about 32 days in Japan. The system of caring, both regional medicine and social welfare, is adjusted to enable patients to receive health care at home after leaving the hospital. Fourth, there is a 'social assistant', and qualification for this position requires vocational education. It is a crossover between nursing and caring. Social assistants play an active role in caring facilities and home caring. In Denmark, they are called social health caregivers.

When we visited hospices and palliative care units in the United Kingdom and Sweden, we attended Tomoko Hansson's lecture about 'Social Welfare in Sweden'. In addition, we visited a group home for people with intellectual disabilities, where we received an explanation about the system of personal assistants for people with disabilities. In February 2012, Hansson's Japanese translation of *Concept and Practice of Caring in Sweden* (Anita Kangas Fyhr and Olga Wilhelmsson, 2012), which is 'a textbook for training staff for nursing and caring in junior high schools', was published. In the preface, Hansson writes about the concept of 'caring': 'It means support for clients from surrounding people so that clients can live as comfortably as possible through nursing, caring, treatment and assistance'. Through this book, people can learn about 'life cycle', 'gerontology', 'the common soil for nursing and caring', 'quality of life and health', 'functional disabilities', 'rehabilitation and aids', 'basis for every day hygiene', 'human engineering and occupational therapy', 'health control of body', 'examination and treatment', 'caring in terminal stage' and 'duties of staff working in facilities for health care'. This textbook provides an educational programme for training people who support client-centred caring by connecting nursing and caring — it repeats the notion of Nightingale as the founder of modern nursing (Kanai, 1998).

The accounts of Stier and Hansson, who have worked in two fields, and the presentation of Dahlberg, who considers the theory of caring through philosophical texts, seem to correspond to one another. Between fieldwork or practice and theory or

philosophy, there is no one-way relationship of influence. Thus, we cannot consider theory or philosophy as a basis for any field or practice, nor that the former is extracted from the latter. However, neither can we think that theory or philosophy is formed independently from any field or practice. There appears to be a corresponding relationship.

### **3. The Concept of 'Lifeworld-Led-Care'**

Here I introduce the background of Dahlberg's article. As previously mentioned, Dahlberg is a member of EACS, a research network connecting five universities — Bournemouth, Brighton, Uppsala, Borås and Linnaeus. The word *European* in the title indicates the intention to build a 'caring science' on theoretical and methodological bases from European philosophy (but including philosophy, ethics, feminist studies, theology, education, alternative and complementary medicine). These researchers wish to synthesize multi-professional and interdisciplinary cooperative work in health care, thus progressing differently from American nursing science.

The three pillars of EACS are lifeworld-led-care, transcultural care and public health. Dahlberg is the pioneer of the lifeworld-led-care concept. The article she contributes, based on her speech in Japan 2011, has been revised to convey her fundamental ideas to Japanese readers. Since readers can directly refer to its contents, I briefly introduce its background.

First, I clarify Dahlberg's positioning of caring science. In Japan, the relationship between caring and nursing has been discussed. Beginning with advocates who insist that 'caring is the essence of nursing science', many discussions have developed about whether caring and nursing are synonymous, whether caring is the kernel of nursing or whether nursing is included within the concept of caring (Hamauzu, 2012c). Nightingale did not distinguish between nursing (nursing care) and caring (welfare care), and thought of 'caring' as encompassing both areas (Kanai, 1998). As previously noted, the idea that 'caring is a common soil of nursing and welfare caring' is widespread in Sweden. Dahlberg's caring science is considered an academic discipline that serves as a basis for nursing and caring. To build caring beyond 'nursing science', Dahlberg constructed 'caring science', which not only includes patients but also

targets healthy people.

The 'lifeworld' concept is also known in Japan. Edmund Husserl, the founder of phenomenology, initiated lifeworld in his last publication, *Crisis of European Sciences and Transcendental Phenomenology* (Husserl, 1954). This concept has been used among phenomenological researchers, but in the 1990s, it spread to disciplines such as sociology, cultural anthropology, folklore, pedagogy, science of religion, social welfare studies and Manga studies. Recently, however, the origin of 'lifeworld as a forgotten meaning fundament of natural sciences' has been forgotten and it is used freely in various disciplines.

This term did not emerge suddenly in Husserl's last publication, but was used earlier to indicate the relationship among various influences. In this sense, it has again received considerable attention (Husserl, 2008). In recent research on the relationships between phenomenology and medicine and nursing and caring, researchers emphasize the contrast suggested by Kleinman (1996) and Toombs between 'disease' as objective judgement by biological medicine and 'illness' as subjective experience by patients. The former is a natural scientific explanation, whereas the latter expresses patients' experiences of lifeworld; thus, the original meaning of 'lifeworld' has been retained (Toombs, 2001). However, in recent nursing science, researchers casually employ this term without considering its origin (Miyawaki, 2012).

Dahlberg takes advantage of the concept of lifeworld to approach the cared-for person's world, which may be foreign to the caregiver. The caregiver must extend him- or herself to identify what the cared-for person sees and hears, is interested in and evaluates what characterizes that person's world. Certainly, the cared-for person does not always see or hear the same thing the caring person does. The cared-for person does not always share the caregiver's world. The former's world could comprise time, space, body, relationship with others, values and view of life that are different from the caregiver's world. 'Caring' becomes possible only by approaching the lifeworld of others.

Moreover, by focusing on lifeworld, we could attend to a patient not as a lonely patient forced into self-decision in a hospital but as a living person who lives at home with family or other people, i.e. a being-in-community.

However, not every patient has a family at home; elderly people in Sweden

seldom live with the younger generation. Nevertheless, as long as they live at home, they have a history including interactions with those around them, whereas hospitalization often means severing these connections. Providing them with care at home after discharge from the hospital helps them recover their lifeworld. Treating a patient or client not as a being-in-hospital but as a being-in-community, who lives interdependently and is supported at home by people around, is facilitated by the caretakers focusing on their lifeworld. Thus, 'lifeworld-led-care' might be regarded as leading to 'community-based-care' (Takenouchi, 2007).

#### **4. 'Lifeworld-Led-Care' from Perspectives of 'At Home' Care and 'Bioethics'**

Although I have contrasted 'at home' and 'in hospital', the phrase 'at home' has different nuances in Japan and Sweden. In the post-World War II era in Japan, over 80 percent of people died at home. Conversely, by 2004, 79.6 percent of people died in hospital. In addition, the percentage of people who die in facilities for the elderly is increasing (Ministry of Health, Labour and Welfare: MHLW, 2004). However, in Sweden, according to 1996 data (Institute for Health Economics and Policy: LHEP, 2001), about 42 percent of people died in hospital; 20 percent at home; and 31 percent in a 'special house'. A 'special house' should not be considered the same as facilities for the elderly in Japan.

Recently, special nursing homes or group homes for the elderly in Japan have developed a system of unit care, i.e. one unit for nine users, and no facilities remain for large groups of people. Although the Japanese learned unit care from Nordic countries, the Japanese version varies from the Nordic. In a group home in Japan, nine users comprise a group, each with his or her own room, extending to approximately 12 m<sup>2</sup>, and a common a living room, dining room, kitchen, bathroom and three restrooms; the home is designed as a single building. In a group home in Sweden, each of the nine or more residents has his or her own home, including a bedroom, living room, dining room, kitchen, shower and toilet. Furthermore, there is a common dining room and living room; this facility is a group of buildings. In addition, because the residents bring their own furniture, they consider themselves 'at home'. From this

background, the 'research about terminal medicine of cared elderly' reports that the rate of death 'at home' is 51 percent including 20 percent 'at home' (in the Japanese sense) and 31 percent in a 'special house' (LHEP, 2002). We must remain aware of the broader Swedish use of the term 'at home'.

Finally, 'lifeworld-led-care' suggests a difference between American and European bioethics. Just like the idea of a 'European Academy of Caring Science', lifeworld-led-care contrasts the European and American ways of thinking. Specifically, American bioethics has emphasized patients' independence and self-decisions; European bioethics admits these qualities, but positions them within solidarity and community. The European view is based on human beings not only having freedom, independence, self-decision and self-responsibility but also helping each other and having interdependent relationships (Council of German Federal Parliament, 2004). This concept could be understood as undergirding autonomy or independence with solidarity and community (Hamauzu, 2012b).

Since the 1990s, Nordic countries have tried to integrate medicine and caring, i.e. transition from the gravity of care in hospitals and facilities to the comfort of care at home (including the 'special house'). This trend includes medicine, nursing and rehabilitation. Indeed, lifeworld-led-care corresponds to at home and community-based care. As previously mentioned, philosophy or theories and practice have a complex relationship. Lifeworld-led-care is not directly connected with clinical fields, nor is there a one-sided influence. Nevertheless, I reassert that practice and philosophy correspond. Lifeworld-led-care should be a philosophy of caring that corresponds to Nordic caring centred at home.

## 5. Nordic Caring from Perspectives of Welfare and Palliative Caring

Dahlberg also emphasizes the interaction of theory and practice. She characterizes the lifeworld approach by its 'open attitude', considering it the antithesis of 'method' (2008). Her article published in this issue leans towards theory, although it is based on fieldwork. And although her lifeworld-led-care theory is based on fieldwork, we cannot yet confirm whether it drives or supports practice. This article introduces her theory, including its background. At the same time as a point of view

from fields that lacks there, I link Dahlberg's theory to the following articles by Takenouchi and Saito.

Takenouchi (Shizuoka University), who has long been engaged with end-of-life and palliative care (Takenouchi, 2009), returned to Japan in May, after his yearlong stay as a visiting professor at Borås University. During his stay, he visited various fields, interacted with members of those fields, visited many researchers and collected exchanges of opinions and discussions. He emphasizes thinking from the perspective of what influences fields, and arranged a visit to palliative and welfare care facilities in the United Kingdom and Sweden, where we had productive discussions with staff and researchers. It was due to him that we were able to attend Hansson's lecture and visit a group home for people with intellectual disabilities. This fiscal year, Takenouchi launched collaborative research titled 'Elucidation of philosophical cornerstones of end-of-life-care in the secularising European society', wherein he discusses Nordic caring by focusing on welfare care, specifically for people with disabilities.

Saito (Bunri University of Hospitality), who also visited fields of palliative and welfare care in the United Kingdom and Sweden, learned Swedish in Uppsala University and worked as a nurse in a palliative care unit in Japan. Currently, besides constructing a nursing system after the Great East Japan Earthquake and Tsunami in March 2011, she participated in the study trip, learned about Dahlberg's research and gained many ideas, especially in palliative care. After visiting palliative care units in Sweden and Scotland and comparing their characteristics, she discusses lifeworld-led-care from the perspective of palliative care.

The abovementioned contributions complement Dahlberg's article and demonstrate original Nordic caring development from perspectives of welfare and palliative care. What Dahlberg calls 'open attitude' as an antithesis against 'method' means reciprocation between top-down and bottom-up. It also means a 'dynamic relationship' between 'Things themselves' and 'method' (Sakakibara, 2009). Nordic caring studies need such reciprocation so the cited articles complement each other.

The common basis of Nordic caring that surfaces from Dahlberg's lifeworld-led-care, Takenouchi's welfare care and Saito's palliative care seems to be 'caring-at-home'. Of course, at home care is not restricted to Nordic countries and is also seen also in other Western countries and Japan. Although various countries practice forms of at home care, it underpins Nordic caring; thus, focusing on it is

perhaps the most important lesson from Nordic caring. In the next and last section, I consider the Japanese situation.

## 6. Caring 'At Home' in Japan Through Nordic Caring

In Japan, the situation concerning medicine and caring at home has changed over several years. In 2006, the system of 'clinics supporting home care' was introduced to facilitate the elderly's living at home and in a familiar community while receiving care. Importantly, they can choose to live their final moments at home surrounded by familiar people. This, however, requires a system that makes medical staff available for house calls 24 hours a day, 365 days a year, as per necessity. Without a networking team, a single-doctor clinic cannot implement such care. Such a system also needs the cooperation of visiting nurses, care managers, a centre of supporting regional care and hospitals that could accept patients if necessary.

According to the working paper of the Japan Medical Association Research Institute, 'Current status and issues of clinics supporting home care' (2011), the number of 'clinics supporting home care' has reached 18,052 facilities across Japan, but a bias exists among regions and medical fees. The paper reported that entry into home care remains small, that for clinics supporting home care and clinics not in the system but providing home care, maintaining the motivation to continue is difficult. Furthermore, it reported that 20 percent of clinics cannot ensure cooperative medical facilities and beds to implement the system 24 hours a day.

Considering all of the above, the project 'Home medicine and caring 2011' (MHLW, 2012) has begun, in which the 'promotion of home medicine and care' is declared and the 'regional comprehensive care system' is conceived. This includes 'strengthening cooperation of medicine and caring in areas of everyday life', 'enrichment of caring service', 'promotion of prevention', 'ensuring various services supporting life', 'consolidation of houses for the elderly that are barrier free, enabling them to live there into advanced age'. Further, as 'a promoting project of home medicine and caring', the project declares, 'cultivation of human resources carrying team of home medicine and caring', 'consolidation of basis as implementation sites', 'enrichment of service according to each disease' and the budget for this fiscal year is

recorded.

Although this project does not seem inadequate, because of limitations on medical bills and the economic situation of hospitals, affected by revised medical fees depending on the length of a patient's stay, the elderly must often be discharged. In other words, the elderly living alone are compelled to return home because another accepting hospital cannot be found and because of a shortage of public facilities. This causes great anxiety among patients. Although the system of home medicine and caring is not sufficiently prepared, the governmental limitation on medical bills means that patients who cannot provide for themselves must leave hospitals. Several years ago, many patients hoped to 'die at home', not 'die in hospital', even if it was difficult to accomplish. Patients cannot 'die in hospital' anymore because national policy restricts medical bills. Thus, patients are compelled to 'die at home', but without professional preparation for 'home care'.

But how is it beneficial for Japan to learn from Sweden about advanced home medicine and caring as well as lifeworld-led-care? According to me, Japan's national policy includes many irrelevancies in procedure and deals with immediate issues, in many cases without a fundamental philosophy. Considering Japan's future, a transition to home medicine and caring should be made; this is what the citizens hoped for. The system and current status (fieldwork and practice) do not sufficiently support it, but the current national consciousness, view of life and death and philosophy supporting home care cannot alleviate the situation. However, lifeworld-led-care, which supports medicine, nursing, caring and welfare, could make accessible the cared-for person's world and support their end-of-life-care.

As stated at the beginning of this article, our research on Nordic caring has only reached its third year. We are newcomers among the many researchers interested in the caring and welfare of Nordic countries. However, as mentioned earlier, although many researchers on the welfare system and caring studies have visited Nordic countries, it is not enough to clarify their system's theoretical grounds and philosophical backgrounds. The theoretical foundation of caring in a wider sense, including medicine, nursing, caring and welfare for our super-aged society is urgently needed, and our research is expected to greatly contribute to it.

## Conclusion

After the gigantic earthquake in eastern Japan and the catastrophic Fukushima nuclear power plant accident, people have become intensely interested in social security issues and the tax system on the one hand, and in issues of anti-nuclear power and natural energy on the other. This situation could be termed an issue of society and environment sustainability for future generations. Compared to Japan, Sweden has promoted the vision of a 'green welfare state' since 1996. Issues of sustainability of the social and environmental systems are not discrete, but intertwined, with a common basis — the concept of caring not only in human relationships but also in the relationships between human beings and nature.

Incidentally, the Swedish Embassy in Japan regularly publishes a periodical called *Caring* to introduce Sweden to the Japanese people. This highlights the importance Swedish people place on caring, even at the price of a high tax burden. But without understanding the philosophy of care or caring in human activities, Japan cannot understand the Swedish emphasis on caring that it should consider adopting.

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## Chapter 15

# CARING UND PHÄNOMENOLOGIE — AUS DER SICHT VON HUSSERLS PHÄNOMENOLOGIE DER INTERSUBJEKTIVITÄT —

### Einleitung

Nach der Publikation meiner Dissertation *Husserls Phänomenologie der Intersubjektivität*<sup>1</sup> begann ich, mich mit dem neuen Thema „Care“ oder „Caring“ zu beschäftigen, das ich als eine Variation von Intersubjektivität oder auch Intentionalität verstehe. Damit ist nicht nur ein interdisziplinäres Thema gemeint, das gemeinsam mit Forschern aus verschiedenen Disziplinen wie Soziologie, Psychologie, Pädagogik, Anthropologie, Medizin, Krankenpflege u.a. zu bearbeiten wäre, sondern auch ein Berührungs punkt von Theorie und Praxis. Aus diesem Grund habe ich mit verschiedenen Forschern und Praktikern zusammengearbeitet und eine *Einleitung zur Anthropologie des Caring*<sup>2</sup> herausgegeben, worauf ich hier leider nicht ausführlich eingehen kann. Obwohl ich mich lange mit dem Thema „Caring“ ohne direkten Bezug zur Phänomenologie Husserls befasst habe, begann ich in den letzten Jahren, eine Brücke zwischen „Caring“ und der Phänomenologie zu schlagen, dies werde ich in diesem Beitrag näher erörtern.

Zunächst aber möchte ich einen kurzen Überblick zum „Caring“ geben und dann prüfen, ob Husserls Phänomenologie den Akt oder die Handlung des „Caring“ gut beschreiben und aufklären kann. Ich werde daher andere Phänomenologen wie Heidegger oder Merleau-Ponty im Folgenden nicht berücksichtigen können, selbst

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<sup>1</sup> Shinji Hamauzu: *Husserls Phänomenologie der Intersubjektivität* (in japanischer Sprache). Tokio 1995.

<sup>2</sup> Shinji Hamauzu (Hg.): *Einleitung zur ‘Anthropologie des Caring’* (in japanischer Sprache). Tokio 2005.

wenn sie das Phänomen „Caring“ noch besser behandelt haben sollten.

## 1. Was ist „Caring“?

Es gibt viele japanische Wörter, welche wir als Übersetzungen des englischen Wortes „Care“ benutzen können. Da man je nach thematischem Bereich unterschiedliche Übersetzungen verwendet, gewinnt man bisweilen den Eindruck, als ob man jeweils mit einer anderen Sache zu tun hätte. Aus diesem Grund gebrauchen wir oft den englischen Terminus als Lehnwort ohne Übersetzung. In der deutschen Sprache verhält es sich meiner Meinung nach ähnlich. Als Übersetzung von „Care“ kommen z.B. Pflege, Sorgfalt, Versorgung, Betreuung, Sorge, Vorsicht, Fürsorge, Obhut, Mühe, Zuwendung und Achtsamkeit in Frage, selbst wenn wir uns nur auf das Nomen beschränken. Auch in der deutschen Sprache könnte dann eine ähnliche Situation entstehen, in der wir die Identität der Sache nicht erfassen können, da sie mit jeweils anderen Wörtern bezeichnet wird. Ich möchte also mit dem Wort „Care“ bzw. „Caring“ hier die Gemeinsamkeiten von Geburtshilfe, Kinderpflege, Krankenpflege, Alterspflege, Behindertenpflege, Pflege am Ende des Lebens, Sterbehilfe usw. zum Ausdruck bringen.

Das Wort „Care“ ist im Englischen so allgegenwärtig, dass es auch kleine Kinder im Alltag verstehen und benutzen. So sagt z.B. die Mutter zu ihrem Kind, das morgens das Haus verlassen und in die Schuhe gehen will: „Take care!“ Gegenstände, worauf wir uns mit dem Akt von „Care“ richten, müssen nicht unbedingt Personen sein, sondern können auch Lebewesen, Pflanzen oder sogar Dinge sein. Weiterhin können wir den Ausdruck auch für Beziehungen, Gemeinschaften oder Staaten verwenden. Ich möchte hier jedoch den Gebrauch von „Care“ auf Personen begrenzen, damit meine Ausführungen nicht zu umfassend und vage werden. Wenn ich mich auf Personen beschränke, könnte man sagen, dass wir Menschen mit „Care“ durch den Anderen geboren sind, mit „Care“ durch den Anderen Tag für Tag leben und mit „Care“ durch den Anderen früher oder später sterben und begraben werden. Das Wort soll hier also in einem sehr weiten Sinne verstanden werden.

Unter einem anderen Gesichtspunkt lassen sich in den Bedeutungen von „Care“ wenigstens zwei Aspekte unterscheiden. Einerseits bezieht es sich auf Sorge oder

Fürsorge im Sinne einer Einstellung oder Gemütsverfassung, in der wir uns um jemanden sorgen, wie es sich in der Wendung „care *about* somebody“ findet. Andererseits bezieht sich das Wort auch auf eine konkrete Handlung, Behandlung oder Technik, mit der ich mich um jemanden kümmere, wie es in der Wendung „care *for* somebody“ zum Ausdruck kommt. Kurz gesagt, das Wort „Care“ vereint die beiden Aspekte einer Gemütseinstellung und einer Tat als Handlung. Weiterhin können wir sagen, dass diese Einstellung oder Handlung keine *negativen* Beziehungen auf den Gegenstand des „Care“ enthält, wie z.B. zerbrechen, verletzen oder bedrohen, sondern nur eine *positive* Beziehung wie schützen, verbessern, heilen oder erziehen. Mit dem Begriff des „Caring“ möchte ich eine solche *positive* Beziehung zu den Anderen thematisieren, während ich zugleich in einem gewissen Maße die Beziehung zu mir selbst (d.h. „self care“) leider nicht in Betracht ziehen kann.

Vorläufig können wir sagen: „Care for or about somebody“ bedeutet, jemandem gegenüber eine *positive* Einstellung zu haben und auch etwas Gutes für ihn zu tun. Zwischen meiner Überzeugung, etwas Gutes für ihn zu tun, und seiner eigenen Überzeugung kann jedoch eine Kluft entstehen, d.h. es ist nicht sicher, ob auch die andere Person glaubt, dass das, was ich tue, etwas Gutes für sie ist. Was ich für gut für jemanden halte und Entsprechendes tue, könnte für ihn eine unnötige Sorge bedeuten oder ihm sogar als etwas Schlechtes erscheinen. Andererseits kann es vorkommen, dass ich nicht an ihn denke und nichts für ihn tue, und das könnte für ihn dennoch als eine achtsame Sorge erscheinen und vielleicht sogar etwas Positives für ihn bewirken. Auf Grund dieser Diskrepanzen bei der Interpretation einer Haltung oder Tat können viele Verständigungsprobleme und auch ethische Probleme im Kontext des „Caring“ entstehen, worauf ich hier ebenfalls nicht näher eingehen kann.

Weiterhin müssen wir uns fragen, ob „Caring“ eine *einseitige* Gemütsverfassung oder Handlung ist, oder ob es eine *wechselseitige* Handlung oder ein gemeinsamer Akt ist, welcher nur in der wechselseitigen Beziehung vollzogen werden kann. Ich möchte mich hier auf die Frage konzentrieren, ob ein so verstandenes „Caring“ mit den Methoden der Phänomenologie, vor allem mit deren Urform bei Husserl, angemessen begriffen werden kann oder nicht.

## 2. Kann eine Analyse der Intentionalität den Akt des „Caring“ aufklären?

Der ursprüngliche Gedanke Brentanos, von dem ausgehend Husserl sein Konzept der Intentionalität entwickelte, lässt sich meines Erachtens in folgenden vier Thesen zusammenfassen:

Erstens, die *Immanenz-These*: „Jedes psychische Phänomen ist durch das charakterisiert, was die Scholastiker des Mittelalters die intentionale (auch wohl mentale) Inexistenz eines Gegenstandes genannt haben“<sup>3</sup>.

Zweitens, die *Richtungs-These*: Intentionalität ist dasjenige, „was wir, obwohl [in] nicht ganz unzweideutigen Ausdrücken, die Beziehung auf einen Inhalt, die Richtung auf ein Objekt [...] oder die immanente Gegenständlichkeit nennen würden.“<sup>4</sup>

Drittens, die *Korrelations-These*: „In der Vorstellung ist etwas vorgestellt, in dem Urteil ist etwas anerkannt oder verworfen, in der Liebe geliebt, in dem Hasse gehasst, in dem Begehrten begehrte usw.“<sup>5</sup>

Viertens, die *Fundierungs-These*: „Wir dürfen es [...] als eine unzweifelhaft richtige Bestimmung der psychischen Phänomene betrachten, dass sie entweder Vorstellungen sind oder [...] auf Vorstellungen als ihrer Grundlage beruhen.“<sup>6</sup>

Solange wir bei diesen Thesen Brentanos bleiben, können wir den Akt des „Caring“ auf der Grundlage seines Intentionalitätsbegriffs wohl nicht hinreichend aufklären. Husserl hat jedoch Brentanos Verständnis von Intentionalität nicht geteilt, sondern ist Schritt für Schritt darüber hinausgegangen. Er begann in den *Logischen Untersuchungen* (1900/01) mit der Intentionalität der Sprache und trat in den *Ideen I* (1913) deutlich einen Schritt nach vorn, und zwar zu einer Analyse der Intentionalität der Wahrnehmung. Schon hier kritisierte er Brentanos *Immanenz-These* und wurde auf diese Weise zur phänomenologischen Reduktion geführt.<sup>7</sup> Dazu bemerkte Klaus

<sup>3</sup> Franz Brentano: *Psychologie vom empirischen Standpunkt*. Erster Band. Hamburg 1924. 124.

<sup>4</sup> Ibid. 124 f.

<sup>5</sup> Ibid. 125.

<sup>6</sup> Ibid. 120.

<sup>7</sup> Da ich dies in meiner Dissertation bereits erörtert habe, möchte ich diesen Punkt hier nicht weiter ausführen.

Held in seiner *Einleitung* zu Husserls Phänomenologie: „Mit dem Begriff der Intentionalität erledigt sich so im Prinzip das klassische Problem der neuzeitlichen ‚Erkenntnistheorie‘, wie ein zunächst weltloses Bewusstsein die Beziehung zu einer jenseits seiner liegenden ‚Außenwelt‘ aufnehmen könne“.<sup>8</sup>

In diesem Zusammenhang möchte ich aber besonders darauf aufmerksam machen, dass Husserl in den *Ideen I* einen neuen Punkt aufgreift, der Brentanos Begriff der Intentionalität noch fremd war. An einer Stelle, an der Husserl von der Intentionalität im Sinne der *Richtungs-These* spricht, bemerkt er: „Wir verstanden unter Intentionalität die Eigenheit von Erlebnissen, ‚Bewußtsein von etwas zu sein‘. Zunächst trat uns diese wunderbare Eigenheit [...] entgegen im expliziten *cogito*“ (III/1, 188). Dieses „explizite“ oder „aktuelle“ *cogito* wird mit der Metapher des Blicks wie folgt gekennzeichnet: „In jedem aktuellen *cogito* richtet sich ein von dem reinen Ich ausstrahlender ‚Blick‘ auf den ‚Gegenstand‘ des jeweiligen Bewußtseinskorrelats, auf das Ding, den Sachverhalt usw. und vollzieht das sehr verschiedenartige Bewußtsein von ihm“ (III/1, 188). Es wird jedoch sogleich hinzugefügt, „daß nicht in jedem Erlebnis diese vorstellende, denkende, wertende, [...] Ichzuwendung zu finden ist, dieses *aktuelle* Sich-mit-dem-Korrelatgegenstand-zuschaffen-machen, Zu-ihm-hin-gerichtet-sein [...], während es doch Intentionalität in sich bergen kann“ (III/1, 188 f.). Dieses Zitat beschreibt die *Richtungs-These* mit der Metapher des „Blickes“, zeigt aber zugleich an, dass diese Richtung nicht nur vom „aktuellen *cogito*“ gilt. Mit anderen Worten: „Ein Gefallen, ein Wünschen, ein Urteilen u.dgl. kann im spezifischen Sinne ‚vollzogen‘ sein, nämlich vom Ich, das in diesem Vollzuge sich ‚lebendig betätigt‘ [...] ; es können aber solche Bewußtseinsweisen sich schon ‚regen‘, im ‚Hintergrunde‘ auftauchen, ohne so ‚vollzogen‘ zu sein. Ihrem eigenen Wesen nach sind diese Inaktualitäten gleichwohl schon ‚Bewußtsein von etwas‘“ (III/1, 189). Mit dem Gegensatz von „vollzogen“ und „regen“ oder analog von „aktuell/explizit“ und „inaktiv/implizit“ behauptet er, dass sich im Hintergrund der sich auf einen Gegenstand *aktuell* richtenden Intentionalität schon eine *inaktuelle* Intentionalität (später auch „Horizont-Intentionalität“ genannt) verbirgt. Diese Erweiterung der *Richtungs-These* stellt ein wichtiges Ergebnis der Theorie der Intentionalität in den

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<sup>8</sup> Klaus Held: Einleitung. In: *Die phänomenologische Methode. Ausgewählte Texte I*. Stuttgart 1985. 25.

*Ideen* Idar, wie schon Ludwig Landgrebe klarstellte.<sup>9</sup> Das könnte hilfreich für meinen Versuch sein, „Caring“ mit Hilfe der Intentionalität aufzuklären. Aber nun möchte ich auf den zweiten Punkt eingehen, der sich auf die *Fundierungs-These* bezieht.

Im direkten Kontext der oben angeführten Stelle schreibt Husserl: „ein Wahrnehmen ist Wahrnehmen von etwas, etwa einem Dinge; ein Urteilen ist Urteilen von einem Sachverhalt; ein Werten von einem Wertverhalt; ein Wünschen von einem Wunschverhalt usw.“(III/1, 188). Soweit stimmt dies noch mit der oben genannten *Korrelations-These* überein, es heißt jedoch im Folgenden: „Handeln geht auf Handlung, Tun auf Tat, Lieben auf Geliebtes, sich Freuen auf Erfreuliches usw.“(III/1, 188). Diese Erweiterung der Intentionalität bezieht sich dagegen eher auf die *Fundierungs-These*. Die Intentionalität, die zuerst mit Beispielen der Wahrnehmung erörtert wurde, wird in den folgenden Paragraphen Schritt für Schritt erweitert <schon vorher „Erweiterung“ daher evtl.: entfaltet/weiterentwickelt?>, z.B. durch „Erinnerung“, „Erwartung“ und „Phantasie“ (§ 91), „Aufmerksamkeit“ (§ 92), eine „höhere Bewußtseinssphäre“ (§ 93), z.B. „Urteil“ (§ 94) sowie die „Gemüts- und Willenssphäre“ (§ 95). Dazu heißt es bei Husserl, indem er die Metapher der „Schichten“ benutzt: „Dabei sind die Schichtungen, allgemein gesprochen, so, daß oberste Schichten des Gesamtphänomens fortfallen können, ohne daß das Übrige aufhörte, ein konkret vollständiges intentionales Erlebnis zu sein, und daß auch umgekehrt ein konkretes Erlebnis eine neue noetische Gesamtschicht annehmen kann; wie wenn z.B. sich auf eine konkrete Vorstellung ein unselbständiges Moment ‚Werten‘ aufschichtet, bzw. umgekehrt wieder fortfällt. Wenn in dieser Art ein Wahrnehmen, Phantasieren, Urteilen u.dgl. eine es ganz überdeckende Schicht des Wertens fundiert, so haben wir in dem *Fundierungsganzen*, [...] verschiedene *Noemata*, bzw. *Sinne*“(III/1, 220). Diesem Modell folgend, schichtet sich auf eine Vorstellung ein unselbständiges Moment von „Werten“, „Gemüts- und Willenssphäre“ auf. Husserl schreibt hierzu weiter: „Andererseits verbinden sich mit den neuartigen Momenten auch *neuartige Auffassungen*; es konstituiert sich ein *neuer Sinn*, der in dem der unterliegenden *Noese* fundiert ist, ihn zugleich umschließend. Der neue Sinn bringt eine total *neue Sinnesdimension* herein, mit ihm konstituieren sich keine

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<sup>9</sup> Ludwig Landgrebe: *Der Weg der Phänomenologie: das Problem einer ursprünglichen Erfahrung*. Gütersloh 1963. 41 ff.

neuen Bestimmungsstücke der bloßen ‚*Sachen*‘, sondern *Werte der Sachen*, Wertheiten, bzw. konkrete Wertobjektitäten: Schönheit und Hässlichkeit, Güte und Schlechtigkeit; das Gebrauchsobjekt, das Kunstwerk, die Maschine, das Buch, die Handlung, die Tat usw.“(III/1, 267). Obwohl die Wertungen fundiert sind, konstituiert sich in ihnen ein neuer Sinn. Hier wird die *Fundierungs-These* in Frage gestellt.

Nach Emmanuel Lévinas verzichtete Husserl seit den *Logischen Untersuchungen* auf die *Fundierungs-These*, indem er behauptet, dass sowohl ein nicht-theoretischer Akt als auch ein theoretischer Akt einen neuen Gegenstand konstituiert. Dies führt ihn zu dem Gedanken, dass ein Kontakt mit der Welt der Werte nicht deren theoretisches Erkennen enthält. Lévinas würdigt gerade dieses Schwanken Husserls: Obwohl seine Phänomenologie damit noch nicht von der Erkenntnistheorie befreit sei, trete sie hiermit aus dem engen Rahmen der Erkenntnistheorie heraus und suche den Platz des Seins im konkreten Leben. Und Lévinas beendete sein Werk mit folgendem Satz: „Mais, la possibilité même de dépasser cette difficulté ou fluctuation dans la pensée de Husserl, n'est-elle pas donnée avec l'affirmation du caractère intentionnel de la vie pratique et axiologique?“<sup>10</sup> Diese Frage können wir unseres Erachtens nach bejahen.

### 3. Entwicklung der Intentionalität in den *Ideen II*

Was Lévinas mit seiner Deutung schon vorausahnte, wurde von Husserl in den *Ideen II* weiter entwickelt, von denen Levinas jedoch keine Kenntnis hatte. Dort schreibt Husserl z.B.: „Wertende Akte [...] können sich auf vorgegebene Gegenständlichkeiten beziehen [...]. Es sind nicht nur überhaupt fundierte Gegenständlichkeiten und in *diesem* Sinn Gegenständlichkeiten höherer Stufe, sondern eben als spontane Erzeugnisse sich ursprünglich konstituierende und nur als solche zu möglicher originärer Gegebenheit kommende Gegenständlichkeiten“(IV, 7 f.). Der Wert als Gegenstand des Wertens erweist sich hier als ursprünglich konstituiert, und er ist ein Gegenstand, der als solcher zu originärer Gegebenheit kommt.

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<sup>10</sup> Emmanuel Lévinas: *La Théorie de l'intuition dans la phénoménologie de Husserl*. Paris 1930. 223.

Vom „Werten“ heißt es dort weiter: „Wir hatten früher einander gegenübergestellt das bloße sehende Bewußthaben des blauen Himmels und den theoretischen Vollzug dieses Aktes. Wir vollziehen das Sehen nicht mehr in dieser ausgezeichneten Weise, wenn wir, den strahlend blauen Himmel sehend, im Entzücken darüber leben. Tun wir das, so sind wir nicht in der theoretischen oder erkennenden, sondern in der Gemütseinstellung“ (IV, 8). Husserl bemerkt hierzu weiter: „Verstehen wir unter ‚Werten‘, ‚Werthalten‘ das Gemütsverhalten, und zwar als ein solches, *in dem wir leben*, so ist es kein theoretischer Akt. [...] es (Wert) ist Angeschautes, aber nicht nur sinnlich Angeschautes [...], sondern *axiologisch Angeschautes*“ (IV, 8 f.). Das Werten ist eine nicht in Vorstellungen fundierte „axiologische Anschauung“. Aus diesem Grund folgert Husserl: „Die ursprünglichste Wertkonstitution vollzieht sich im Gemüt als jene vortheoretische (in einem weiten Wortsinne) genießende Hingabe des fühlenden Ichsubjektes, für die ich den Ausdruck *Wertnehmung* schon vor Jahrzehnten in Vorlesungen verwendet habe. [...] Der Ähnlichkeit sollte die Ausdrucksparallele *Wahrnehmen* — *Wertnehmen* Ausdruck geben“ (IV, 9 f.). Um es kurz zu sagen/Kurz gesagt: Das *Wertnehmen* vollzieht sich nicht fundiert in dem *Wahrnehmen*, sondern beide liegen auf dem gleichen Niveau der Unmittelbarkeit, so dass die *Fundierungs-These* hier schon aufgegeben ist.

Ich habe bereits die Metapher des „Blicks“ in den *Ideen I* erwähnt und auch deren Zusammenhang mit der *Richtungs-These* angedeutet. Obwohl Husserl z.B. hinsichtlich der Wahrnehmung von „Blickrichtungen des reinen Ich auf den von ihm vermöge der Sinngebung ‚gemeinten‘ Gegenstand“ (III/1, 202) spricht, weist er in den *Ideen II* auf Folgendes hin: „In gewissem allgemeinen Sinn richtet sich zwar überall das Ich auf das Objekt, aber im besonderen Sinn geht mitunter ein vom reinen Ich vorschließender Ichstrahl auf das Objekt hin und kommen von diesem gleichsam *Gegenstrahlen* entgegen“ (IV, 98). Oder: „Das Ich ist das identische Subjekt der Funktion in allen Akten desselben Bewußtseinsstroms, es ist das *Ausstrahlungszentrum*, bzw. *Einstrahlungszentrum* alles Bewußtseinslebens, aller *Affektionen und Aktionen*, [...] *Tuns und Leidens* usw.“ (IV, 105). Hier wird der „Blick“ mit einer Ausstrahlung aus dem Ich verglichen, aber als eine solche Ausstrahlung, die zugleich von der Einstrahlung von den Dingen her affiziert und bedingt ist. Obwohl die Intentionalität der *Richtungs-These* zufolge einseitig zu sein scheint, wird hier eine Passivität als Gegenrichtung angedeutet. Auch hierin liegt meiner

Meinung nach ein hilfreicher/wichtiger? Hinweis, wie wir „Caring“ als einen Fall von Intentionalität aufklären können.

Dies wird noch klarer im Übergang vom Gesichtssinn zum Tastsinn. Während Husserl in Bezug auf den Gesichtssinn von einer Art Doppelstrahlung spricht, weist er für den Tastsinn auf die Doppelempfindung als eine eigentümliche Doppelheit und Umwandlung des Sinnes hin. In der auch von Merleau-Ponty zitierten bekannten Stelle der *Ideen II* beschreibt Husserl Folgendes: „Die linke Hand abtastend habe ich Tasterscheinungen, d.h. ich empfinde nicht nur, sondern ich nehme wahr und habe Erscheinungen von einer weichen, so und so geformten, glatten Hand. Die anzeigen den Bewegungsempfindungen und die repräsentierenden Tastempfindungen, die an dem Ding ‚linke Hand‘ zu Merkmalen objektiviert werden, gehören der rechten Hand zu. Aber die linke Hand betastend finde ich auch in ihr Serien von Tastempfindungen, sie werden in ihr ‚lokalisiert‘, sind aber nicht Eigenschaften konstituierend [...]. Spreche ich vom *physischen* Ding ‚linke Hand‘, so abstrahiere ich von diesen Empfindungen [...]. Nehme ich sie mit dazu, so bereichert sich nicht das physische Ding, sondern *es wird Leib, es empfindet*“ (IV, 144 f.). Diese bekannte Analyse der Doppelempfindung vom „Tasten der linken Hand mit der rechten Hand“ hat Merleau-Ponty in seiner *Phénoménologie de la Perception* inspiriert und ihm den ersten Schritt zu dem Gedanken der „intercorporeité“ ermöglicht.

Da sich eine solche Doppelempfindung nur im Tastsinn ereignen kann, bemerkt Husserl im Hinblick auf den Gesichtssinn: „Ähnliches haben wir *nicht* beim *rein visuell sich konstituierenden Objekt*. Man sagt zwar mitunter ‚das Auge, über das Objekt hinblickend, tastet es gleichsam ab‘“ (IV, 147). Unmittelbar danach erläutert er dies jedoch wie folgt: „Aber wir merken sofort den Unterschied. Das Auge erscheint nicht visuell, und es ist nicht so, daß an dem visuell erscheinenden Auge dieselben Farben als Empfindungen lokalisiert erscheinen [...] Und desgleichen haben wir keine ausgebreitete Augenhaftigkeit derart, daß fortschreitend Auge an Auge entlanggehen und das Phänomen der Doppelempfindung entstehen könnte; [...] Ich sehe mich selbst, meinen Leib, nicht, wie ich mich selbst taste. Das, was ich gesehenen Leib nenne, ist nicht gesehenes Sehendes, wie mein Leib als getasteter Leib *getastetes Tastendes* ist“ (IV, 147 f.). Hier stellen wir fest, dass Husserl Intentionalität nicht nur mit Hilfe des Gesichtsinnes, sondern auch mit Hilfe des Tastsinnes verstehen will, und dass er beim Tastsinn nicht nur eine einseitige Beziehung, sondern eine

wechselseitige Beziehung anerkennt.

In der hier nachgezeichneten Entwicklung von den *Ideen I* zu den *Ideen II* sehen wir deutlich, dass alle oben genannten Thesen zu Brentanos Intentionalitätsbegriff aufgegeben, erweitert oder verändert wurden. Obwohl Husserl bis zur Spätzeit Formulierungen wie Intentionalität, Noesis und Noema sowie *cogito* und *cogitatum* durchgängig verwendet, verändert sich ihr Inhalt. In dieser Veränderung des Sinnes von Intentionalität finden wir für die Diskussion der Bedeutung des „Caring“ wichtige, hilfreiche Hinweise. Ich werde nun noch einen anderen Aspekt diskutieren, der die verschiedenen Arten der Intentionalität betrifft.

#### **4. Zwei Arten der Intentionalität in den *Ideen II***

In den *Ideen II* bezeichnet Husserl die Einstellung der Naturwissenschaften als „naturalistisch“, die Einstellung der Geisteswissenschaften und auch diejenige des Alltagslebens jedoch als „personalistisch“. Wenn wir uns auf den Menschen (oder den konkreten Anderen) richten, treten beide Einstellungen als zwei verschiedene Arten der Intentionalität hervor. Um es klar und einfach zu formulieren, schlage ich vor, die „naturalistische“ Einstellung als *Einstellung auf die Natur*, hingegen die „personalistische“ Einstellung als *Einstellung auf die Person* zu bezeichnen. In der erstenen richten wir uns auf den Menschen (oder den konkreten Anderen) als Gegenstand des naturwissenschaftlichen „Erklärens“, während wir uns in der letzteren auf den Menschen (oder den Anderen) als Gegenstand des geisteswissenschaftlichen „Verstehens“ richten. Da die Einstellung auf die Person auch die Seinsweise unserer Mitsubjekte im alltäglichen Leben charakterisiert, sollten wir in diesem Zusammenhang eher nicht von „Gegenständen“ sprechen.

Die Differenz der beiden Einstellungen wird heute oft durch die Gegenüberstellung von „Caring“ (als die Pflege des Kranken) und „Curing“ (als dessen medizinische Behandlung) ausgedrückt. Meines Erachtens entspricht „Cure“ der *Einstellung auf die Natur*, hingegen das „Care“ der *Einstellung auf die Person*. Beim „Curing“ versuche ich, den Anderen in der *Einstellung auf die Natur* zu beobachten, seine Körpervorgänge zu erklären und zu behandeln, während ich beim „Caring“ den Anderen in der *Einstellung auf die Person* zu verstehen beabsichtige,

seinen seelischen und leiblichen Bedürfnissen entsprechen und ihm helfen möchte. Um dem Sinn des „Caring“ in seiner besonderen Intentionalität aufzuklären, finden wir meines Erachtens nach bei der *Einstellung auf die Person* einen Anhaltspunkt. Im Folgenden werde ich dieser Idee folgen und den Kontrast beider Einstellungen genauer untersuchen.

Husserl äußert sich über die *Einstellung auf die Natur* folgendermaßen: „Sie [d.h. ichliche Zustände] werden, wie Seelisches überhaupt, in der naturalistischen Erfahrung dem physisch erscheinenden Leibe bei- bzw. ‚eingelegt‘, mit ihm in der bekannten Weise lokalisiert und temporalisiert. Sie gehören in den Verband der realen (substantial-kausalen) Natur“ (IV, 181). Dies betrifft auch den ganzen Menschen: „Dieser Mensch dort sieht und hört, vollzieht auf Grund seiner Wahrnehmungen die und die Urteile, die und die Wertungen und Wollungen in vielgestaltigem Wechsel. Daß ‚in‘ ihm, diesem Menschen dort, ein ‚Ich denke‘ auftaucht, das ist ein Naturfaktum, fundiert in dem Leibe und leiblichen Vorkommnissen, bestimmt durch den substantial-kausalen Zusammenhang der Natur, die eben nicht bloße physische Natur ist, während doch die physische die alle sonstige Natur begründende und mitbestimmende ist“ (IV, 181). In der *Einstellung auf die Natur* halten wir also den Körper (oder den Leib) und die Seele des Anderen für ein Naturfaktum innerhalb der Naturkausalität und erklären sein Verhalten sowie seine körperlichen Vorgänge (d.h. wir naturalisieren ihn); in der *Einstellung auf die Person* dagegen leben wir als Person in der Gemeinschaft: „Ganz anders ist die *personalistische Einstellung*, in der wir allzeit sind, wenn wir miteinander leben, zueinander sprechen, einander im Gruße die Hände reichen, in Liebe und Abneigung, in Gesinnung und Tat, in Rede und Gegenrede aufeinander bezogen sind“ (IV, 183). In dieser Einstellung halten wir den Anderen für eine Person, mit welcher wir zusammen leben, zu welcher wir sprechen, der wir zum Gruße die Hände reichen usw. Deswegen schreibt Husserl: „Es handelt sich also um eine durchaus natürliche und nicht um eine künstliche Einstellung“ (IV, 183).

Zur naturalistischen Einstellung bemerkt er: „Wer überall nur Natur sieht, Natur im Sinne und gleichsam mit den Augen der Naturwissenschaft [sieht], ist eben blind für die Geistessphäre, die eigentümliche Domäne der Geisteswissenschaften. Er sieht keine Personen und aus personalen Leistungen Sinn empfangenden Objekte — also keine ‚Kultur‘-Objekte“ (IV, 191). In der *Einstellung auf die Natur* sehen wir

den Anderen nicht als eine Person, sondern als Naturobjekt. Ganz anders verhält es sich in der *Einstellung auf die Person*: „in der *komprehensiven Erfahrung vom Dasein des Anderen* verstehen wir ihn also ohne weiteres als personales Subjekt und dabei auf Objektitäten bezogen, auf die auch wir bezogen sind: auf Erde und Himmel, auf Feld und Wald, auf das Zimmer, in dem ‚wir‘ gemeinsam weilen, auf ein Bild, das wir sehen usw.“ (IV, 191). In der *Einstellung auf die Person* interpretieren wir den Anderen als eine Person und beziehen uns auf eine gemeinsame Umwelt.

Kurz gesagt: Das Verhältnis zwischen Person und Person besteht darin, dass die Personen mit der Absicht, untereinander verstanden zu werden, eine Handlung vollziehen und eine Wirkung auf den jeweiligen Anderen ausüben, sowie darin, dass der eine auf das Wirken hin wieder eine Reaktion zeigt, die an den Anderen gerichtet ist. Das ist kein Verhältnis der „Kausalität“, sondern der „Motivation“. So beschreibt Husserl die Fremderfahrung: „Einfühlung ist nicht ein mittelbares Erfahren in dem Sinn, daß der Andere als psychophysisch Abhängiges von seinem Leibkörper erfahren würde, sondern eine unmittelbare Erfahrung vom Anderen“ (IV, 374). Weiter schreibt er: „Ähnliches gilt von der Erfahrung der Kommunikation mit Anderen, des Wechselverkehrs mit ihnen. Sehen wir einander in die Augen, so tritt Subjekt mit Subjekt in eine unmittelbare Berührung. Ich spreche zu ihm, er spricht zu mir, ich befehle ihm, er gehorcht. Das sind unmittelbar erfahrene personale Verhältnisse“ (IV, 374). Also erfahre ich den Anderen unmittelbar, und zwar motiviert (d.h. mit einer gewissen Passivität), und indem ich mich in ihn einfühle (d.h. mit einer Aktivität).

Husserl verwendet das von Theodor Lipps entlehnte Wort „Einfühlung“, obwohl er es von Anfang an kritisiert hat. Wenn ich diesen Terminus recht verstehe, bedeutet er nichts anderes als das, was Husserl schlicht als „Fremderfahrung“ bezeichnet. Hierzu äußern sich Gallagher und Zahavi folgendermaßen: „empathy, properly understood, is not a question of feelingly projecting oneself into the other, but rather an ability to experience behaviour as expressive of mind, i.e. an ability to access the life of the mind of others in their expressive behaviour and meaningful action.“<sup>11</sup> Es ist „eine Art der Erfahrung“ gemeint, in der wir den Anderen als eine Person erfahren und seine Intentionalität unmittelbar verstehen. Obwohl die Phänomenologie

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<sup>11</sup> Shaun Gallagher/Dan Zahavi: *The Phenomenological Mind — An Introduction to Philosophy of Mind and Cognitive Science*. London 2008. 213.

bisweilen so verstanden wird, als ob sie auf die Perspektive der *Ersten Person* ein Licht werfen kann, könnte die Fremderfahrung auch so verstanden werden, als ob sie auch eine Phänomenologie aus der Perspektive der *Zweiten Person* ermöglicht. Hierzu noch einmal Gallagher/Zahavi: „One of the frequent claims made by defenders and detractors alike is that the distinguishing feature of a phenomenological approach to the mind is its sustained focus on the first-person perspective. As we have also tried to show, however, this is an overly narrow definition.“ Sie behaupten weiter: „Phenomenological analyses of the nitty-gritty details of action, embodiment, intersubjectivity, and so on, provide more than simply a description of first-person experience. In numerous investigations of how the subjectivity of others manifests itself in gestures, expressions, and bodily behaviour, phenomenologists have also provided detailed analyses from the second-person perspective“.<sup>12</sup> Es könnte meines Erachtens für die Intentionalität des „Caring“ hilfreich sein, auf diese Weise/in diesem Sinne? die „Intentionalität des Anderen“ aus der Perspektive der *Zweiten Person* zu betrachten.

## 5. Zwei Arten der Person als Anderer

Nun komme ich zu meinem letzten Schritt, um den Begriff des „Caring“ mit Hilfe der Intentionalität zu beschreiben. Das Wort „Person“ benutzt man auch im grammatischen Sinne, wie „Erste Person“ (ich), „Zweite Person“ (du) und „Dritte Person“ (er, es, sie). Auf der Grundlage der oben genannten Differenz der Einstellungen kann man sagen, dass es in der Einstellung auf die Natur nicht um die Person geht, während es in der Einstellung auf die Person gerade um diese geht, und zwar auch im grammatischen Sinne. In den Situationen, in denen es sich nicht um die Person handelt, benutzt man normalerweise nur die Form der „Dritten Person“. In derjenigen Einstellung hingegen, in der es um die Person geht, treten oft die sprachlichen Formen der „Ersten Person“ und der „Zweiten Person“ auf. Wenn wir also das Problem des Zugangs zum Anderen bzw. der Fremderfahrung diskutieren wollen, müssen wir den Unterschied zwischen dem Anderen in der „Dritten Person“ und dem Anderen in

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<sup>12</sup> Gallagher/Zahavi: *The Phenomenological Mind*. 240.

der „Zweiten Person“ in Betracht ziehen. Obwohl gelegentlich die Probleme des Verhältnisses von „Ich und Anderem“ und desjenigen von „Ich und Du“ vermengt werden, muss man zwischen beiden unterscheiden. Es sieht nämlich so aus, als führe die Zweite Person eher als die Dritte Person zum Verständnis dessen, was „Caring“ ist.

Nebenbei bemerkte, unterschied Martin Buber zwei verschiedene „Haltungen“ zum Menschen mit den „Grundwörtern“ oder „Wortpaaren“ „Ich – Du“ und „Ich – Es“. Dem ersten Anschein nach meint man, dass „Ich – Du“ ein Verhältnis zu Personen bedeutet, hingegen „Ich – Es“ ein Verhältnis zu einem Ding. Genau besehen differenziert Buber eher zwischen der Zweiten Person und der Dritten Person als zwischen Person und Ding, weil „ohne Änderung des Grundwortes für Es auch eins der Worte Er und Sie eintreten kann“<sup>13</sup>. Er grenzt bei der Diskussion des Anderen also das Problem des „Du“ (Zweite Person) von demjenigen des „Es“ (Dritte Person) ab.

Wenn Husserl in den ersten Analysen der II. *Logischen Untersuchung* <meint er evtl. nicht eher die I. Logische Untersuchung?> vom „Ausdruck in kommunikativer Funktion“ (§ 7) spricht, sagt er, dass der „Hörende“ den „Sprechenden“ als „eine Person, die nicht bloß Laute hervorbringt, sondern zu ihm spricht“ versteht, also in einer Situation, in welcher der „Sprechende“ dem „Hörenden“ einen Sinn „mitteilen will“. Aber Husserl bezeichnet hier sowohl den „Sprechenden“ als auch den „Hörenden“ als „er“, also in der Form der „Dritten Person“ (XIX/2, 39). Im Gegensatz dazu erscheint in einer Anmerkung zu den *Ideen II* und in einer Beilage (abgefasst zwischen 1913 und 1917), in der Husserl das Problem der „Person“ behandelt, der Kontrast zwischen „Ich und Du“ (IV, 277. 319). Auch in einem Text aus dem ersten der Intersubjektivitätsbände (geschrieben 1910/11) erwähnt Husserl „Ich-Du-Akte“ (XIII, 88). Obwohl diese Formulierung uns an Martin Bubers oben genanntes Werk erinnert, kann es Husserl nicht beeinflusst haben, weil bei diesem schon sehr von „Ich und Du“ die Rede ist, wie z.B. in der 1914 niedergeschriebenen These: „das Ich konstituiert sich erst im Kontrast zum Du“ (XIII, 247). Die erste Erwähnung des „Du“ findet sich in einem Text des ersten Intersubjektivitätsbandes aus dem Jahr 1908: „Dein Bewusstsein ist für mein Bewusstsein *absolutes* Aussensein, und mein

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<sup>13</sup> Martin Buber: *Ich und Du*. Leipzig 1923. 9.

Bewusstsein für dich“(XIII, 6). Auch in anderen Texten der *Husserliana* findet sich bisweilen der Ausdruck „Du“(Z.B. IV, 289; XXV, 167; VIII, 232; VIII, 232; IX, 215; IX, 228 usw.).

Die fünfte *Cartesianische Meditation*, in der Husserl die Fremderfahrung als „Einfühlung“ diskutiert, wurde bisher von vielen Forschern kritisiert. Einige dieser Kritiken beruhen meines Erachtens aber auf Missverständnissen. Hier möchte ich nur darauf hinweisen, dass sich dort die Urform der Fremderfahrung in der „Paarung“ als einer Form der „passiven Synthesen“ findet. Husserl behauptet dort, „daß ego und alter ego immerzu und notwendig in ursprünglicher Paarung gegeben sind“(I, 142). Aber diejenigen, die sich da „paaren“, sind doch nicht „ich und er/sie/es“, sondern „ich und du“. Husserl selbst konnte aber die Besonderheit der „Paarung“ hier nicht im präzisen Zusammenhang von „ich und du“ erörtern, obwohl er an anderer Stelle dieses Textes „Ich-Du-Akte“ erwähnt.<sup>14</sup> Trotzdem scheint mir hierin ein Hinweis zu liegen, der zu einer Phänomenologie des Du führen könnte.

Derzeit suche ich nach einem Weg zur Phänomenologie des Du bei Husserl. Obwohl es bei ihm nicht viele Stellen gibt, die uns hierbei leiten können, finden sich jedoch meines Erachtens einige Äußerungen, in denen Husserl gerade einige dem „Caring“ entsprechende Wendungen benutzt, so z.B.: „In der natürlich erwachsenen Familiengemeinschaft sehen wir leicht, dass das Erste die natürlich naiv erwachsende Fürsorge der Mutter für die Kinder, des Mannes für die Mutter als Gattin und als Mutter der Kinder usw. ist“(XIV, 180). Das Wort „Fürsorge“ lässt sich ins Englische mit „Care“ übersetzen. Oder betrachten wir folgende Aussage Husserls: „sowie ich abstraktiv schon den Anderen im Weltfeld habe [...], habe ich ihn auch als wertendes und praktisches Mitsubjekt, aber auch als Objekt, Objekt meiner Sorgen, meiner Tätigkeiten etc.“(XV, 134 f.) Auch das Wort „Sorge“ lässt sich mit „Care“ wiedergeben. Obwohl es noch weitere Stellen gibt, an denen Husserl ähnliche und damit verwandte Ausdrücke verwendet(XIV. 165 f.; 167; 175 usw.), kann ich diese hier leider nicht näher interpretieren.

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<sup>14</sup> Husserl: *Cartesianische Meditationen*. Hg. und eingeleitet von Elisabeth Ströker, 135. Diese Ausdruck fehlt jedoch in der entsprechenden Stelle von Hua I. 159.

## 6. Schluss

Wir haben festgestellt, dass Husserl die vier Brentano'schen Thesen zur Intentionalität, d.i. Immanenz, Richtung, Korrelation und Fundierung, schon in der Entwicklung von den *Ideen I* zu den *Ideen II* in Frage stellte und auf einige der Teilthesen verzichtet hat. Die Intentionalität, die zu Anfang, und zwar wegen der Deutungen Brentanos, für die Beschreibung des „Caring“ ungeeignet zu sein schien, könnte dafür in der hier vorgestellten Umdeutung durch Husserl durchaus eine Möglichkeit eröffnen. Wenn Intentionalität sich nämlich nicht nur auf die Gemütsverfassung, sondern auch auf die Handlung bezieht, wenn sie nicht nur einseitig, sondern wechselseitig ist, und wenn sie aus dem Hintergrund und dem Horizont affiziert und motiviert, somit ein wechselseitiger Akt ist und damit keine bloße Beobachtung der Natur bezeichnet, sondern eine Handlung zum Nutzen einer Person enthält, und wenn sie nicht zuletzt einen Weg zu einer Perspektive der Zweiten Person, des „Du“, eröffnet, dann können wir sagen, dass es nicht unmöglich ist, den Sinn des „Caring“ mit Hilfe des so verstandenen Begriffs der Intentionalität aufzuklären. Aber eine konkrete Beschreibung dessen, was für ein Akt „Caring“ ist, können wir in Husserls Texten nur bruchstückweise finden. Ich sehe deshalb meine künftige Aufgabe darin, den Sinn des Caring mit Hilfe anderer Texte Husserls zur Intersubjektivität, Lebenswelt und Ethik aufzuklären.

## Chapter 16

### INTERSUBJECTIVITY OF AGEING — READING BEAUVIOR'S *THE COMING OF AGE* —

#### 1. Opening Words: My background

I have been engaged with Husserl's phenomenology of intersubjectivity for a long time. Twenty years ago I published my dissertation just titled "Husserl's phenomenology of intersubjectivity", and years later published 6 the Japanese translation of Husserl's *Cartesian Meditations*, then 3 years ago the first volume of Husserl's *Phenomenology of Intersubjectivity* (Husserliana Vol.13 to 15), 2 years ago the second. And the third volume would be published soon in this October.

I have been also engaged with the problem of caring in a wide sense including stages from birth, ageing, disease and death. These four phenomena just mentioned are called the "four sufferings" by Buddha. However my interest doesn't lie in the Buddhism, but in the contemporary situation around these phenomena which are totally changed especially after the World War II, partly because of the so-called medicalization. About this theme I'm giving lectures at the university, as well as organizing symposia outside the university with citizens.

For a couple of years I have been trying to build a bridge between both of my interests, phenomenology of intersubjectivity and caring in the contemporary society. Two years ago I read a paper titled "Caring and Phenomenology from the Husserlian point of view of Intersubjectivity" at an international conference organized by Husserl-Archive in Cologne, Germany.

Now I come to Finland. I met Prof. Sara Heinämaa at first at the conference of the Phenomenological Association of Japan in 2007 when she gave an impressive talk about Husserl's ethics in Kaizo article. In 2009 I took part in the conference of Nordic

Society for Phenomenology in Tampere and read my paper “Narrative and Perspective”. In 2010, I was an examiner for a doctoral thesis by a Japanese female researcher titled “Freedom and acknowledgement — Ethical thoughts of Simone de Beauvoir” in which the author emphasized the influence of Edmund Husserl in Beauvoir’s early writings. I also read Heinämaa’s excellent work *Toward a Phenomenology of Sexual Differnce — Husserl, Merleau-Ponty, Beauvoir*. When I stayed in Helsinki for a week two years ago and had a chance to discuss my interests mentioned above with her, I found we have a common interest in many points and would like to make a collaboration with her.

In this March Heinämaa stayed in Osaka and gave a lecture and a seminar in Osaka University. I was very impressed with her lecture titled “Ageing and Death: A phenomenological-Philosophical Approach” based on her paper “Transformations of Old Age - Selfhood, Normativity, and Time” on Beauvoir’s book *The Coming of Age*. In this summer semester, from April to July, I gave a lecture on Old Age in which I talked about ageing from various perspectives just in a similar way as Beauvoir developed in her book and by quoting her book at some important points. Simultaneously in a seminar of the same period I read Husserl’s Text, *Husserliana* vol.42, *Grenzprobleme der Phänomenologie*, namely *Problem on limits of phenomenology*. Now I would like to begin with Beauvoir’s work and go on to discuss Husserl’s work.

## **2. The first part “Old age seen from without” of Beauvoir’s work *The Coming of Age***

Beauvoir’s work is composed of two parts: the first part “Old age seen from without (outside)” and the second part “The being-in-the-world”, in other words old age seen from inside. We can consider the first part as empirical studies based on empirical sciences such as biology, ethnology, history and sociology, whereas we can consider the second part as philosophical studies with existential or phenomenological tendency, based on description from first person perspective, by quoting literature and autobiography by various authors. In “Preface” of the book she declared her idea of such composition and called it “interdependency” of both perspectives from

outside and inside or “a principle of circularity” between exteriority and interiority. In order to philosophize on ageing according to her idea we need such a “total perspective” which I find very appropriate. I would like to begin my reading with her empirical studies in the first part, but I also take note that such empirical studies are almost of date, because this book was written in 1970, namely 45 years ago. We must therefore update some information of this part.

## 2-1. The first chapter “The old age and biology”

In my lecture I've updated some important points of knowledge from biology, medicine and gerontology, for instance that activated oxygen wounds DNA of our body, that cell division is limited because of telomere, that multicellular organism with sexual reproduction is composed of somatic cells and germ cells, that telomere limits the life of somatic cells, whereas telomerase resets the life of germ cells, and that this makes a biological programme of ageing and death of human being. Beauvoir quoted Dr. Escoffier-Lambiotte, “that ageing and subsequent death... occur when a set programme of growth and ripening reaches its end”(25). This programme which makes ageing and death “the law of life” has been almost proved by modern molecular biology of DNA.

Nevertheless Beauvoir's opinions about biological gerontology are not out of date. She wrote: Gerontology's “conclusions are of the very highest interest, and old age cannot possibly be understood without reference to them. But they cannot tell the whole story. ... A man's ageing and his decline always takes place inside some given society”(36). “What so complicates the whole problem is the close interdependence of all these points”(9), such as a biological phenomenon, psychological consequences and an existential dimension, or in other words: “I shall look upon it as a complete entity, tying it in with the biological, existential and social context, accordingly to the principle of circularity”(33).

## 2-2. The second chapter “The ethnological Data”

I've added some points about Japanese history, because Beauvoir didn't mention any historical considerations regarding ideas about aging in Japan. For example,

Beauvoir did not mention the Ainu, indigenous people in northern island of Japan before influenced by Japanese civilization, and old customs to abandon the old described by Japanese Novel “Narayama”, mountains of death, by Fukazawa Shichiro. Beauvoir wrote: “Many societies respect the old so long as they are clear-minded and robust, but get rid of them when they become senile and infirm”(51). However, it isn’t clear whether Fukazawa’s Novel describes a real event, because it is presented as a fiction, and is based on a legend. Generally speaking, she wrote, “we may infer that the most usual choice of communities with inadequate resources, ... is to sacrifice the old. ... When a society has a certain margin of security, there seems on the face of it to be a reasonable supposition that it will maintain its aged people”(81). In such a society “the aged men and women are in close relationship with the children. ... The old person, being freed from the labour of the adults, has time to look after the young; and in their turn they have the leisure to provide their grandparents with the services they need”(84f.). She called it an “exchange of kindness”(ibid.), where we can find an origin of taking care of the elderly.

### 2-3. The third chapter “Old age in historical societies”

At the beginning of the third chapter Beauvoir wrote: “It is impossible to write a history of old age”(88). In 1987, 17 years later after her book, a French historian Georges Minois published “Histoire de la vieillesse en occident : de l’Antiquité à la Renaissance (History of the old age in the Western countries: from the ancient to Renaissance)”. Although Beauvoir’s historical study is limited to Western societies with only one exception China, very shortly, and also to mainly literature and writings by novelist, philosophers and politicians, not any historical documents, it covers up to 20th century and the next chapter “Old age in present-day society” follows it. In this sense Beauvoir’s historical study is much wider than Minois’ historical work.

In my lecture I introduced some Japanese books on a history of old age in Japan written by some Japanese historians. “In the twentieth century”, Beauvoir writes, “the urbanization of society continued, and one of its consequences was the disappearance of the patriarchal family”(208). In Japan there was a restoration of *Tenno* (emperor) system after collapse of the *shogunate* (feudalistic government by *shogun*) in the second half of 19th century. In this system the patriarchal family was

very strong. Although at last at the end of Second World War II, 1945, the system with the patriarchal family was abandoned, it remains underground in various customs of Japanese postwar society. In such situation the caring for children as well as the elderly in family was forced to women, housewives in Japan. This situation is now slowly changing.

Beauvoir wrote, “Taken as whole, the advance of industrialization has led to a progressive dissolution of the family unit. The marked ageing of the population that has been observed these last years in the industrial countries has forced the community to take the place of the family. Society has adopted a policy with regard to old age”(209). Just in 2000, 30 years later than Beauvoir’s book, Japan has introduced a system of socialization of caring in place of the family after the problem of ageing of population has been begun to be discussed widely.

#### 2-4. The fourth Chapter “Old age in present-day society”

In the fourth chapter Beauvoir quoted Sauvy’s words “The least debatable of all the phenomena of our day, the surest in its progress, the easiest to foresee far ahead and perhaps the most pregnant with consequences is the ageing of the population”(221), and wrote about the situation of France in those days: “In October 1969 there were 6.3 million persons aged over sixty-five in France, or more than twelve per cent of the population”(221). In Japan of same year the ratio of ageing of the population was about 7 per cent, but became over 14 per cent in 1995 and more than 25 per cent last year, namely 31.9 million persons aged over sixty-five, one fourth of population. Japan’s ratio of ageing of population lies now on the top of the world and Japan is so to speak a super-aged society which any country has never experienced. From there it can happen what Beauvoir never imagined in those days of France.

Beauvoir wrote. “In the capitalist democracies, the ageing of the population has raised new difficulties. ... Old age has become the object of a policy”(222). After she mentioned “pensions”, “a system of social insurance” by Bismarck in Germany, she wrote, “Of the capitalist countries, there are three that look upon it as an imperative duty to ensure decent conditions for all citizens; there are Denmark, Norway and Sweden”(225). Nowadays we could add Finland to such so-called social welfare countries. From such background I’m also interested in the social caring system for

the elderly in Finland in which I can't unfortunately enter today. In any case it is worthy to reconsider the problem of ageing beyond Beauvoir's book *The coming of age* from this side.

### 3. The second part “Being-in-the-world”

As I've pointed at the beginning, Beauvoir in the first part “looked at the aged man as an object, an object from the scientific, historic and social point of view: we have described him from the outside”, whereas she in the second part will describe him “who is also subject and has an intimate, inward knowledge of his state and who reacts it”(279). We remember the idea of “interdependency” or “the principle of circularity” I pointed out already. Beauvoir denied it to be a “dilemma” and introduced another idea about it as follows: “it is a dialectic relationship between my being as he (the outsider) defines it objectively and the awareness of myself that I acquire by means of him”(284). But on the other hand she called it “contradiction” too, as follows: “We must assume a reality that is certainly ourselves although it reaches us from the outside and although we cannot grasp it. There is an insoluble contradiction between the obvious clarity of the inward feeling that guarantees our unchanging quality and the objective certainty of our transformation. All we can do is to waver from the one to the other, never managing to hold them both firmly together”(290). But this idea of “an insoluble contradiction” is in my opinion against the idea of “a dialectic relationship”.

In this context Beauvoir mentioned Sartre's term: “old age belongs to that category which Sartre calls the unrealizable”(291). According to Sartre's idea, “It is impossible for us to experience what we are for others in the for-itself mode: the unrealizable is ‘my being seen from without which bounds all my choices and which constitutes their reverse aspect’”(291). She wrote also: “Old age is something beyond my life, outside it - something of which I cannot have any full inward experience. But when she introduced Sartre's term “the unrealizable” and distinguished between the realizable and the unrealizable, this idea seems me to be again against the idea of “a dialectic relationship” and also against the idea of “interdependency” and “the principle of circularity”.

In relation to Sartre's term "the unrealizable", I would like to comment and to introduce a often misunderstood idea of "empathy" for experience of the other (Fremderfahrung) which he characterized "accessibility of original unaccessibility" (CM, 117). In other words, by criticizing Leibnitz's thought "Monad has no window", Husserl insisted: Monad has "reell" (Husserl used a French word in distinction from a German word "real") no window, but has "intentional" a window which is called "empathy". According to Husserl's term, we can say, what is "reell" "unrealizable" could be "intentional" "realizable". But back to Beauvoir's book.

### 3-1. The sixth chapter "Time, activity, history"

The same inconsistency happened not only with the problem of old age, but also with the problem of death in the sixth chapter. She wrote: "Death belongs to that category in which we have placed old age and which Sartre calls the 'unrealizables'; the for-itself can neither reach death nor project itself towards it; death is the external limit of my possibilities and not a possibility of my own" (441). Also here she was caught in a trap of Sartrean dualism of "being-for-itself" and "being-for-other" instead of a "dialectic relationship" between them.

It turns out also with the title of the second part "Being-in-the-world". This term originated as you know from Heidegger's work *Being and Time*. It was translated to "Being-in-the-world (Etre-dans-le-monde)" by Sartre, whereas Merleau-Ponty translated it as "Being-to-the-world (Etre-au-monde)", because human being in the world is totally different from things in the world. The central idea for it lies in the idea of "living body" or "lived body" which he learned by Husserl's idea of "Leib" or "mein Leib" different from "Körper". This idea which Merleau-Ponty laid in the center of his book *Phenomenology of Perception*, lacks in Beauvoir's discussion of "body's experience" in the fifth chapter, i.e. the first chapter of the second part, titled "The discovery and assumption of old age: the body's experience", in my opinion. Therefore at the sole passage, where this term appeared, she could write: "Death has one element that runs throughout all history: by destroying our organism it wholly does away with our being in the world" (440). In this passage it seems me that she reduced "being in the world" to the sole "organism", but not the "ambiguous" being of "my living body" which Merleau-Ponty characterized as an object and a subject

simultaneously.

### 3-2. The seventh chapter “Old age and everyday life”

From the beginning Beauvoir distinguished between ageing and death, by saying: “Disease is contingent, whereas ageing is the law of life itself”(28). Nevertheless ageing, disease and death are intertwined with each other especially in the super-aged society as Japan. The cause of death in a year is ranked in Japan, cancer on the top, heart attack on the second, pneumonia on the third and brain attack at the fourth place. And the ratio of old age among dying people is very high. In caring for the elderly the important problem lies in paralyzed patients after brain attack as well as in patients with dementia. Just here we find a point of contact between ageing and disease. Nowadays in Japan the elderly with dementia is estimated to amount 4.6 million, 15 per cent of the elderly. And if we count “Mild cognitive impairment” as a beginning step to dementia, it is estimated to amount 4 million, and if we count this MCI together with dementia, it is estimated to be totally 8.6 million, one among four aged persons. The problem of dementia is now a crucial one in Japan.

I find it interesting and pioneering that Beauvoir described the problem of mental disorders with old age by quoting some works by psychiatrists such as Henry Ey, Freud, Minkowski and Kraepelin. She wrote: “Mental illnesses are more frequent among the old than among any other age-group. Yet they were very poorly understood until the end of the 19th century: they were all grouped under the single heading of senile dementia. ... Yet since old age is a ‘normal abnormality’ it is still often difficult to draw the line between the mental disturbances that ordinarily accompany ageing and those which are of a pathological nature”(493). Further she reported the situation in those days: “It (senile dementia) has become more frequent in recent years because the number of old people has increased. ... It has assumed a considerable social importance, and because of the destruction of the family-unit and the consequent need to look after the patients in hospital, it arouses difficult problems. Living conditions have great influence upon the appearance and evolution of the disease”(499f.).

At the end of this chapter she quoted Dr Repond’s words: “it is reasonable to wonder whether the old concept of senile dementia, the alleged result of cerebral

disorders, should not be entirely overhauled, and whether these pseudo-dementias are not the result of psycho-sociological factors ... We even go to far as to claim that the clinical picture of senile dementia may be an artifact, due in the majority of cases to shortcomings in the treatment and in the attempts at prevention and rehabilitation"(503f.). I find this idea very important especially for the present-day situation of Japan, but unfortunately she didn't develop this idea much more in this book.

#### 4. A Quotation from Husserl

Before ending my reading of Beauvoir's book, I would like to make a comment about Prof. Heinämaa's article and lecture which I mentioned above. Her interest is concentrated on philosophical investigations which Beauvoir described mainly in the second part of her book. At the prologue of her lecture and original paper Prof. Heinämaa quoted the following passages: "Also I myself will die — like I was once born, developed into adulthood and got old. But the question is, what this means". And she began her comment as follows: "This statement could well be from Simone de Beauvoir's late work, *The Coming of Age*, but it could equally well belong to Sartre's or Merleau-Ponty's reflections on the temporality of the human condition. It comes, however, from a more distant source which is less familiar to contemporary feminist theorists and philosophers of life: the quote is from Husserl's reflections on the finiteness of human existence". Certainly the statement originates from Husserl's manuscript titled "The anthropological World" written at the end of 1936, contained in Husserliana vol.29.

However, I must add a comment to her comment on the quotation. The statement was quoted from the manuscript mentioned above and from a paragraph titled "living in the world and dying of human and transcendental subjectivity". The statement quoted from almost the middle of this paragraph is related to living and dying of human subjectivity. But Husserl concluded at the end of this paragraph and also of this manuscript as follows: "The human being cannot be immortal. The man dies inevitably. The human being doesn't have any worldly pre-existence. In the temporal-spatial world he didn't have anything before and won't be anything later.

But the transcendental original life, the ultimate world-creating life and its ultimate I cannot be generated from nothing and go away into nothing. It is ‘immortal’, because death for it has nonsense”(XXIX, 338). Husserl distinguished here the mortality of human subjectivity and the immortality of transcendental subjectivity.

## 5. From Cartesian Egology to Leibnizean Monadology in Husserl’s Phenomenology of Intersubjectivity

Also in texts of *Phenomenology of Intersubjectivity* which I translated into Japanese we can find the same distinction at least at the beginning of his considerations where he started with Cartesian egology. For instance in a manuscript written in 1922 from Husserliana vol.14, Husserl wrote: “The I neither arise, nor vanish, but experiences something always. The pure I which the phenomenological reduction gives us is ‘eternal’ and immortal in one sense. ... On the contrary it is only human being as a member of nature that can be born and die in the natural sense”(XIV, 157). Yet in the context of Leibnitzean monadology, by proceeding from static phenomenology to genetic phenomenology, the question of genesis in the concrete status calls the issues of beginning and ending, interruption, transformation and ripeness into considerations. In a manuscript written at the beginning of 1930s from Husserliana vol.15, he raised issues of “unconsciousness, sedimental ground of consciousness, sleep without dream, state of birth of subjectivity, or being before birth, death and being after death”(XV, 608), and asked: “How far does such a reconstruction reach concerning birth and death?”(XV, 609). We can interpret this “reconstruction” as “constructive phenomenology” which Eugen Fink characterized in his *VI. Cartesian Mediation*(1988). In a manuscript written in 1930s Husserl wrote: “Death is unrepresentable (or in Sartrean term, unrealizable) in the self-considerations (i.e. egological considerations). ... Death gets meaning for me only on the way through understanding of others”(XV, 452). In the solipsistic static phenomenology birth and death cannot have meaning without being on limits of phenomenology, whereas both get meaning in the genetic and further constructive phenomenology regarding the experience of others and even in the transcendental dimension.

We can find a similar thinking in *Problem on limits of phenomenology*,

Husserliana vol. 42 which was published last year and with which I worked in my seminar of this summer semester as written. The problems which Husserl called “the problem of birth and death, transcendental constitution of meaning which both have as events in the world, and the problem of sex “ in *The Crisis of European Sciences and Transcendental Phenomenology* (VI, 192) are just discussed in this volume 42. At the beginning he considered birth and death as events in the constituted world, whereas the constituting subjectivity has neither birth nor death. But when he began to talk about “transcendental life” instead of transcendental subjectivity, he brought birth and death into consideration on the transcendental dimension and began to talk on co-existence on the transcendental dimension, too. In the concrete status of monad limited between birth and death, it gets meaning to take “birth, development of childhood, ripening, ageing and death” of “human being as fellows” into consideration. In this context Husserl discussed on “transcendental other” which “coexistents transcendentally with my transcendental I”(XV, 372). In this context he wrote: “I am through that I am for me and included in the constitution of universe of transcendental co-I (Mit-Ich). I cannot be who I am without that the other being for me isn’t without me. The transcendental inclusion is necessity of transcendental co-existence (XV, 370). Unfortunately I have no enough time to talk about the latest stage of Husserl’s phenomenology of Intersubjectivity, but give only a short comment

Here we find an intertwining relationship between the constituted world where we live or dwell in the natural attitude and the constituting subjectivity or transcendental life which we can find through the transcendental reduction, in other words, an interdependent relationship between phenomenological psychology and transcendental phenomenology which is discussed in the lecture *Phenomenological Psychology* in 1925 (Husserliana IX), or the similar relationship between “ontology of life-world” and transcendental phenomenology which is discussed in the latest publication *The Crisis of European Sciences and Transcendental Phenomenology* in 1936 (Husserliana VI). In my opinion, the “interdependency” or “the principle of circularity” at the beginning of Beauvoir’s book *The Coming of Age* which I emphasized at the beginning of my talk is sympathizing with such a tendency of the latest Husserl.

## **6. Closing words: Caring for the elderly**

In “Conclusion” of her book, Beauvoir wrote: “if we wish the old person’s state to be acceptable”, “it is the whole man that must be re-made, it is the whole relationship between man and man that must be recast. ... A man should not start his last years alone and emptyhanded”(543). And further: “If he were not atomized from his childhood, shut away and isolated among other atoms, and if he shred in a collective life, ... then he would never experience banishment. Nowhere, and in no country, have these conditions obtained. Although socialist countries may have come a little closer to them than the capitalist, they still have a very long way to go”(ibid.). From a similar thinking I’m very interested in Nordic countries with welfare and caring system. It is also the reason why I am interested in Finland.

## Chapter 17

# INTERSUBJECTIVITY OF PERSON-CENTRED CARE: A PHENOMENOLOGICAL PERSPECTIVE

### 1. Opening Words

My background is in philosophy, especially Husserl's phenomenology of intersubjectivity. Twenty years ago I published my dissertation titled "Husserl's phenomenology of intersubjectivity", and a few years later published the Japanese translation of Husserl's *Cartesian Meditations*, then of the three volumes of Husserl's *Phenomenology of Intersubjectivity* (Husserliana Vol.13 to 15).

For 15 years, I have been also engaged with the problem of caring in a wide sense including stages from birth, ageing, disease and death. These four phenomena just mentioned are called the "four sufferings" by Buddha. However my interest doesn't lie in the Buddhism, but in the contemporary situation around these phenomena which are totally changed especially after the World War II, partly because of the so-called medicalization.

With these interests in mind I met Karin Dahlberg in 2009 through the introduction of Marcia Schuback in Södertern University and took part in several meetings on "Caring and Phenomenology" or "Lifeworld-led-care" in Växjö University. Then I organized a interdisciplinary project "Philosophical background of Nordic Caring" supported by Karin with nine members for three years and now am organizing a second interdisciplinary project "Regional and Home Care in Nordic countries" with nine members for three years which is now in the last year.

Last year in October, invited by Lisa Folkmarson Käll, I took part in the International conference at Centre for Dementia Research of Linköping University in Norrköping "Life with Dementia: Relations" and gave a talk titled "Dementia as a

sickness of interpersonal relationship". Today as it's sequel I would like to talk with the title "Intersubjectivity of person-centered-care: a phenomenological perspective" by comparing the situation on dementia care in Japan with the situation in Sweden.

## **2. The present-day situation of ageing and dementia in Japan**

According to WHO the rate of ageing of the population is defined as the rate of more than 65 years old person among the whole population. In Japan, we call a society with more than 7 % of this ratio an ageing society, the society with more than 14 % an aged society, and the society with more than 21 % a super-aged society. Japan became an ageing society in 1970, an aged society in 1994 and a super-aged society in 2007. According to this definition we understand also that if the denominator decreases because of declining birth rate the rate of ageing of population increases even if the total number of aged people doesn't increase. Therefore Japan is now a super-aged society with declining birth rate.

According to the "White Paper on Aged Society" in version of 2014 edited by the Cabinet Office of Japan, the whole population of Japan amounts to 127 million at the present of 1st October 2014 and the population of more than 65 years old amounts to 31.9 million. The rate of ageing of population amounts to 25.1 %, therefore more than one in four persons. In 2035, namely in the future about 20 years later, it is estimated that the rate will be 33.4%, namely one in three persons. In 2060 it is estimated that the rate of more than 75 years old people will amount to 26.9 %, one in four persons.

If we compare the rate of ageing of population in Japan with other European countries, Japan stayed in the middle in 1980s, came to the top of the world at the beginning of 21<sup>st</sup> century and became a super-aged society which no country has experience. As to the speed of ageing the required time from 7 % to more than 14 % of the rate was 115 years in France, 85 years in Sweden, 47 years in UK and 40 years in Germany, whereas it was only 24 years in Japan.

Among the aged people also the number of people with dementia is growing every year. According to the statistic by the Japanese Ministry of Health, Labor and Welfare, the number of people with dementia amounts to 4.6 million in 2012 and it is 15 % of the aged people. Half of the elderly people in Japan are estimated to be

suffering from Alzheimer disease, 20 % from Vascular dementia, 20% from Dementia of Lewy bodies. And if we count “Mild cognitive impairment” as a beginning step to dementia, it is estimated to amount 4 million, and if we count this MCI together with dementia, it is estimated to be totally 8.6 million, one among four aged persons. The problem of dementia is now a crucial one in Japan.

Dementia once used to be considered to be a phenomenon of ageing but now is diagnosed as a disease and an object of medical treatment. There are many different types of dementia, but the best course of action for treating dementia is not yet known. According to psychiatry, dementia has two different types of symptoms: core symptoms (disorders of memory, visual-spatial, language, attention, and executive function) and peripheral symptoms (behavioral and psychological symptoms of dementia: in short BPSD). The core symptoms could be treated medically though it is difficult, whereas the peripheral symptoms could be improved if they are cared well.

### **3. Medical Care for Dementia**

According to the first article of the “National Guideline of Medicine and Caring for Dementia” (2010.5.1) of Sweden, “for the diagnosis of dementia, there must be an elementary investigation by a general doctor shouldering the primary care”. And as far as I’m informed, we must wait for six months until the doctor can diagnose as a dementia. It is a method that is recommended by ICD (International Statistical Classification of Diseases and Related Health Problems) of WHO. The Swedish Guideline calls our attention to the fact that we must not simply rely on examination of machine such as brain imaging. This seems to be a totally different attitude of medicine to dementia from the one in Japan which follows DSM (Diagnostic and Statistical Manual of Mental Disorders) of APA (American Psychiatric Association) and doesn’t demand 6 months for it’s diagnosis.

According to the Japanese Ministry for Health, Labor and Welfare it is recommended to get a medical examination, diagnosis and treatment as early as possible. There are several types of dementia which are curable if they are diagnosed and treated in early stage. Otherwise they become incurable at later stage, and in cases of Alzheimer’s disease it is possible to slow down its progress. If it is treated in

early stage, it make possible to live with health for longer period. But the diagnosis of dementia in an early stage is difficult and demands an advanced examination machine with a skilled technique. An examination at a special medical institution is indispensable. The Ministry recommends therefore that reliable relationships with a special doctor from an early stage are necessary.

People thought for long time that dementia is not a disease, but an inevitable symptom of ageing, and hence incurable. The development of medicine shows that we must distinguish between the symptoms of ageing and dementia as disease. However, dementia has a relatively short history, it seems to be a disease of the modern age and consequently, the method of treatment for dementia is not well established, at least not in Japan. Although the specialism of internal medicine and the psychiatry in Japan have a history of more than 100 years, it is only in last 20 years that dementia is medically understood and becomes an object of medical treatment. Now it is understood, that dementia is not a singular type of disease, but is instead a syndrome, 'dementia' is a name for a collection of symptoms and includes many types of diseases. Alzheimer's disease is one of them, although the rate of it is more than the half of sufferers with dementia in Japan. Beside ATD (Alzheimer Type Dementia) there are other types of dementia such as DLB (Dementia with Lewy Bodies), LPC (Lewy-Pick Complex), VD (Vascular Dementia), FTLD (Frontotemporal Dementia), etc. There are also some treatable dementia such as Chronic Subdural Hematoma and Normal-Pressure Hydrocephalus.

In such instances, a Japanese Doctor, Kazuhiko Kono asserts that dementia is not incurable, it is only that many doctors don't know how to cure dementia, although dementia must be differently treated according to the variety of it. He developed a new method called the "Kono-method" which is now in widespread use in Japan. It is primarily a method of pharmacotherapy. He insists that we need different courses of medication, depending on what type of dementia is diagnosed. If the doctor doesn't know about such diversity of dementia prescribes an incorrect set of medicaments, then patients could fall in an unexpected situation from a side effect of the medicament. If patients with a different type of dementia from ATD get the famous medicament for ATD, called Aricept, then it could happen that they become much worse. Especially DLB have often been diagnosed as ATD for long time and prescribed with an incorrect set of medicament. The quantity of medicaments is important, too. In order that

patients could take a correct set and quantity of medicaments, he leaves how to take medicaments to their family who know the everyday situation of the patient well. He prescribes not only western medicaments but also eastern, alternative medicaments.

Moreover Kono recommends a special supplement made from ferulic acid and garden angelica, called “Feru-guard”. This “Kono-method” seems to be a little suspicious, but is now adopted by more than 200 clinics or hospitals in Japan. Dr. Kono finds it false to think that person with dementia can do nothing and refers the book *Who will I be when I die?* (originally published in 1998, Japanese translation in 2003), written by a patient with dementia in Australia, namely Christine Boden, diagnosed as the early stage of ATD in 1995. But this requires a totally different approach to dementia beyond medical care including “Kono-method”.

#### 4. Person-centered-Care

As mentioned above, various symptoms of dementia are distinguished into core symptoms and peripheral symptoms. The former are cognitive impairments such as memory loss, disorientation and so on, whereas the latter are other behavioral and psychological symptom of dementia (BPSD) such as delusion, hallucination, anxiety, wandering, and aggression and so on. The former can mainly be treated by medical care, whereas the latter can't in such a way, but are changeable, and could be made better or worse by depending on what care is given. If persons with dementia are cared for with dignity, humanity and respect, the peripheral symptoms could disappear. It means that they are not objectified by medicine, but their subjectivity is respected. This leads us from the medical model to the idea of person-centered-care established by Tom Kitwood in UK.

According to the third article of the above-mentioned Swedish “Guideline of Medicine and Caring for Dementia”, “all of medicine, nursing and caring should be based on person-centered-care and a teamwork of multi-professional cooperation”. Also in Japan, this idea of person-centered-care has been well known especially for care workers, since Tom Kitwood's writings such as *Dementia Reconsidered the person comes first* (1997) or *Person-Centred Care* (2000) ed. by Sue Benson were translated into Japanese (both in 2005). Since then the Japanese Society of

Person-Centered-Care was established and is giving mainly caregivers opportunities of a training or workshop of PCC in every big cities in Japan.

Nevertheless, the Japanese Ministry doesn't seem to regard this idea as important when it comes to developing their policy because the concept announced by the Japanese Ministry in 2005 "A decade for getting to know dementia and making a region" intends to make a region where many supporters for dementia live and persons with dementia can live without anxiety. They don't intend to enter into the subjectivity of persons with dementia. It seems to be difficult that the idea of person-centered-care becomes a policy in Japan.

Apart from the Japanese government, the 20<sup>th</sup> international conference of Alzheimer's Disease International (ADI) 2004 took place in Kyoto (Japan), it was reported that the interest in the person-centered-care in Japan is very high and that many people are educated of dementia care mapping (DCM). Another characteristic and noteworthy event of the same conference in Kyoto was that the above-mentioned Christine Boden was invited to a workshop and gave a speech, and that Japanese persons with dementia had an opportunity to stand on the platform and give a speech. The founder of person-centered-care, Tom Kidwood himself, didn't know about Christine Boden's book, published just around his death in 1998. In his book Kidwood gives nevertheless seven approaches to get an insight to the subjective world of dementia, finds the first approach in the description which is written by a person with dementia in the period of having relatively little lost of the cognitive capacity and refers the book *Living in the Labyrinth*, written by Diana MacGowin 1993. If he had a chance to read the book of Christine Boden, he would estimate its value.

Before entering to the subjective world of dementia, I would like to mention the idea of "Humanitude" briefly, which was established by French physical therapists Yves Gineste and Rosette Maresotti and gained a lot of interest in Japan. Just last year it was introduced by a TV program and the Japanese book *Introduction to Humanitude* was published in June of last year. "Humanitude" is a method of recovering dignity and is composed of five techniques, namely of how to "see", "talk", "touch" and "stand". In my opinion, however, they are techniques based on the idea of person-centered-care and are intending to neither change nor add anything to the idea of PCC, although it was sensationaly introduced in Japan as a new method of caring for persons with dementia. I remember that many different ideas such as

“validation” or “dignity therapy” are imported in Japan, but they have been soon forgotten as if they were a fashion. Now I would like to return back to the subjective world of dementia which was opened by the idea of PCC.

## 5. Person-Centred Research of Dementia from First Person Perspective

As I said, Christine Boden’s book, *Who will I be when I die?* (Japanese translation in 2003), and her next book, *Dancing with dementia* (Japanese translation in 2004) were epoch-making also for those working in the caring profession and dementia in Japan. However, the idea that a person with dementia can have a rich original subjective world, has been developed originally also in Japan, without importing. For instance, a film of Sumiko Hada titled *The world of elderly with dementia* (1986) was a documentary about ordinary life of elderly with dementia, and another film titled *Oriume (A broken ume tree, Japanese Apricot, 2001)* described that a person with dementia keeps a creativity with feeling in paintings in spite of having lost memory.

Moreover, the Japanese psychiatrist Isao Ozawa published a book titled *Living Dementia* (2003), in which he described “How is the world from the perspective of elderly with dementia?”, “What do they see, think and feel?” and “What kind of inconvenience do they live?”, by quoting several Japanese novels and mentioning Christine Boden’s book as a rarity, since it was a book written by a person with dementia. In his opinion, most of research on dementia so far was performed about dementia as a disease, or at best about how to care for elderly with dementia. They observed elderly with dementia as an object of their research or treatment. The intention to approach to how sufferers with dementia see their world and where their mind lies, and to accompany with them was very poor. There lacked an attitude to let them speak as a subject and to listen to them. He called the world of person with dementia as “lifeworld”, which stems originally from the founder of phenomenology, Edmund Husserl.

I have already mentioned that at the 20<sup>th</sup> international conference of Alzheimer’s Disease International (ADI) 2004 in Kyoto (Japan), Christine Boden was invited to a workshop and also some Japanese with dementia had a chance to give a talk in front of audience. The DIPEX international, which was founded to promote the spread

worldwide of well researched data on people's personal experiences of illness and health at the University Oxford in UK, was introduced to Japan in 2001 and the DIPEX Japan was founded in 2007. This NPO (Nonprofit Organization) provides now many talks or narratives of person with dementia on the website.

Last year a Japanese TV program introduced an activity named as "Nothing about us without us" which was founded in Scotland. In this activity persons with dementia are working very active as subject. Moreover, in 2012 the Society of Person-Centred Research of Dementia from the first person perspective was founded. It intends to develop not only talks given by persons with dementia, but also researches of themselves, namely about what is their lifeworld, or how they see, think and feel the world. This idea of person-centred research stems in Japan from the regional activity of Bethel's House in Urakawa town of Hokkaido, northern island of Japan, since 1984.

This activity was established as a community and cooperation of persons with mental disorders, mainly schizophrenia, and organized by a social worker Ikuyoshi Mukaiyachi. About six years later after the foundation as a cooperation of working for processing tangles, they began to research themselves from their first person perspective, for instance, about what kind of auditory hallucination or delusion they have, and to present their researches at first in their group as social skill training (SST), and then in front of audience. This activity of Bethel's House brought many writings to the world, was introduced many times in TV program and became now very famous.

Recently books about Person-Centred Research, one by a person with cerebral palsy, another by a person with developmental disorder, Asperger syndrome, were published and this method of research by persons with various disabilities. Based on such a tendency, last year a book titled *Investigation on the Person-centred Research* (2013) was published, in which philosophical scholars discussed the philosophical meaning of the person-centred research from the first person perspective. Moreover last year a Japanese translation titled *Crazy in Japan — Ethnography of Bethel's House* from an English book was published.

The above-mentioned person-centred research of dementia could be settled among such a movement. However I would like to emphasize that also such person-centred research can not be performed only by the first person perspective,

but by the interaction of the first and the second person perspective, namely interpersonal relationship. The person-centred research of Bethel's House was characterized by its founder Mukaiyachi as "By myself, and Together". "By myself" means that researches of mental disorders should not be left in doctor's hands, but performed by oneself, whereas "and Together" means that such person-centred research could be however only be possible through self-help activity with a supporter or in group, namely through interpersonal relationship.

## **6. Intersubjectivity of Person-centered-care and Lifeworld-led-care**

As mentioned above, the peripheral symptoms of dementia could disappear if persons with dementia are cared for with dignity, humanity and respect. It means that dementia is no disease which happens only to an individual, but has especially in its peripheral symptom a character of sickness of interpersonal relationship. Although the person-centered-care seems to be caring for an individual by emphasizing the subjectivity of person with dementia, even the founder of PCC Kitwood emphasized in term of "intersubjectivity" that the most important task is the improvement of quality of interaction. The idea of PCC could be considered to be in a sense a part of paradigm change from paternalism to informed consent. But the problem is how we should understand the word "person". If we understand with it a subject with intellect, mental capacity and self-determination, we could not grasp the problem of dementia well. The person-centered-care should be understood with intersubjectivity. This means just that the person-centered care can change peripheral symptoms of person with dementia. The idea of PCC should not be individualized, but understood as an example of intersubjectively.

Intersubjectivity as a phenomena is always found within a wide context of the above-mentioned "lifeworld", which is mainly composed of "temporality", "spatiality" and "intersubjectivity" in a different sense from scientific understanding. Persons with dementia live in a lifeworld with original temporality, spatiality and intersubjectivity. The person-centered care leads thus to the "lifeworld-led-care" which I learned from a Swedish scholar, Karin Dahlberg. It will attempt to understand what kind of lifeworld the sufferer is dwelling. With this idea not caring at institutions that

is breaken off from lifeworld, but caring at home in a regional lifeworld is reconsidered now.

According to the seventh article of the Swedish Guideline of Medicine and Caring for Dementia, “a commune must endeavor so that persons with dementia can dwell in a small-scale, equipped for individual patient, familiar and plentiful special house”. This idea can be understood as a variation of “lifeworld-led-care”. Compared to the Swedish guidelines, I find the above-mentioned plan of Japanese Ministry poor, which intends to make a region where many supporters for dementia live and persons with dementia can live without anxiety.

## 7. Closing Words

Before I come to Göteborg I spent a week in Helsinki in order to give two talks: the one titled “Dialogue in Husserl’s phenomenology and psychiatry” was read at an interdisciplinary workshop “DIALOGUE AND INTERSUBJECTIVITY” with which the main figure for the new movement “Open Dialogue”, namely Jaakko Seikkula (University of Jyväskylä) took part; the second titled “Intersubjectivity of Ageing — Reading Beauvoir’s The Coming of Age” was read at the seminar for philosophy.

At closing words I would like to mention the new movement of mental health from Finland which is introduced recently in Japan and which we can find a sympathizing idea of “meeting” of the Bethel’s House. It is called “Open Dialogue” which I mentioned above. This method is practically inherited as one method to treatment intervention for patients with schizophrenia, centered in family therapists of Keropudas Hospital in Tornio, west Lappland Finland since 1980s. A team of experts should visit clients in critical situation of acute stage within 24 hours after request and open a dialogue everyday among patients, family and relatives until the situation would improve. This method doesn’t use any medicament, but heal only through conversations. They discuss with all together a method of treatment, a possible pharmaceutical treatment and the pros and cons of hospitalization. They must not decide anything without the person concerned: it is the rule. They say: “In an ambiguous situation just a dialogue gives us a hope and a clue to get out of labyrinth”.

These cases of “meeting” of Bethel’s House in Japan and “Open Dialogue” in Finland we can find that people practices even against the common knowledge of mental medicine in order that the person concerned can recover talking.

Although Japan is now standing at the frontline because of the highest rate of elderly among the whole population in the world, the idea of caring for persons with dementia in Japan is still in developing level. We can learn much more ideas from Nordic countries especially from Finland and Sweden.