Reinterpretation of the scientific approach to the act of Caregiving

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INTRODUCTION

Continuing technological and scientific development in Medicine together with the socio-economical transformations that occurred lately, allowed a substantial increase in the human life span. However, the survival increment does not always mean a functional, independent and healthy life. The number of individuals with loss of autonomy, or who are disabled and handicapped has risen in parallel to the higher prevalence of chronic and incapacitating diseases. In this context, consistent and integrated care for these persons by their relatives and health professionals assumes an increasing importance.

Therefore, this study has two objectives: to investigate the scientific approach to the caregiver and, by characterizing the act of caregiving as something intrinsically human, to put forward an interpretation of this subject which takes into account the patient, the caregiver and the interactions between them.

METHODS

In order to fulfil the proposed objectives, a research in the database PsycInfo about the concept of "caregiver" was initially undertaken. This was followed, in a second stage, by the reinterpretation of this concept according to the "Autopoietic Subject Theory" by Cândido Agra (1990, 2001) and his four theoretical positions and levels.

RESULTS

Concerning the concept of caregiver, thousands of bibliographical references containing the key words "caregiving" or "caregiver" were found in PsycInfo. A quick analysis of the abstracts allowed us to verify that, in these papers, this concept emerged associated with:
- populations with distinct characteristics and problems; a unique definition of this concept don't exist;
- concepts of "burden", "burnout", "quality of life", "well-being", "death" and "grief";
- physical consequences, followed by emotional and cognitive ones;
- four different application areas: dementia, extreme stages of the life cycle, chronic mental diseases and chronic physical diseases (mainly cancer, HIV, brain-vascular and cardiovascular diseases, transplant patients and multiple sclerosis);

In the second stage of the methodology, it was possible to conceptualize four different theoretical positions, both for the patient and for the caregiver (formal or informal) when facing the disease and its clinical manifestations, as well as for the relational environment resulting from the concordant or dissonant dynamics established between the two. The reinterpretation of this new scientific approach to the act of caregiving is systematized in the following tables.

Concerning the first position (Table 1), a total incapacity of adaptation to a new imposed situation is revealed, being prevalent a very negative vision of the world. Everything happens as a result of external forces that do not leave space for an action capable of counteracting the external determinations. Reality is factual and pragmatic, transforming the person into a victim of his/her own incapacity of changing that reality (Agra, 1990, 2001; Guerra, 1998).

Table 1. Comparison of the intervenients at ontological level and substantive position

Patient	Informal Caregiver	Formal Caregiver
- Fatalism, passivity - Acceptance of fate; deterministic reality - Negative state of mind - Increase of disease symptomatology and of negative answers towards the help delivered - Incapacity to find a meaning of life - Restraining attitude in the way of facing interpersonal and institutional relationships - No therapeutic adherence ("there's nothing that can be done")	- Isolation - Revolt - Perception of the facts as unchangeable - Emotional support with little efficacy - Suffering caused by patient's "fatalism" - Incapacity to resort to personal and environmental resources	- There's nothing more that can be done in face of reality - Direct or indirect communication of hopelessness, abandonment and negligence - Give up on the Person because there's nothing that can be done about the disease - Inadequate use of available resources - Not very humanized attitude

In the second position (Table 2) the individuals try to adapt themselves to the situations through external criteria and norms. A higher dependence on external references and exterior support occurs, being the adaptation attempted by imitation or suggestions by others (Agra, 1990, 2001; Guerra, 1998).

Table 2. Comparison of the intervenients at deontological level and solidary position

Patient	Informal Caregiver	Formal Caregiver
- Fatalism towards fate - Incapacity of solving situations and symptoms - Search for answers and solutions in others - Dependent relationship towards healthcare professionals and caregivers - Demands great physical, emotional, relational and temporal availability - Passivity towards the exterior ("sponge that only absorbs from the environment")	- Assumes his/her role without questioning - Incessant search of advice - Rigorously follows recommendations given to him/her by experts or others - Frequently asks patient for opinion and approval, there being the possibility of helping too much (which is negative) - Behaves according to the others' expectations (social desirability) - Incapacity to adapt him/herself to the disease and to the new functions/difficulties - Insecurity towards the caregiver-patient relationship (and its challenges)	- Constant requirement of external support resources (other professionals, family members and institutions) - Practising what is suggested to him/her, feeling dissatisfied with him/herself - Not taking responsibility or decentralization of responsibility

The third position (Table 3) is dominated by vectors of a cognitive nature which organize a subjective logic that reflects a very individualized and solitary procedure of psychological self-production. It characterizes individuals who are not directed towards the outside and who search within themselves the solutions for their problems and conflicts inherent to the disease (Agra, 1990, 1997, 2001; Guerra, 1998).

Table 3. Comparison of the intervenients at logical level and solitary position

Patient	Informal Caregiver	Formal Caregiver
- Very self-centred - Control perception - Use of individual capabilities to face the disease - Little cooperation with the healthcare professionals and caregivers - Perception of resources in the environment as not being very useful - Does not feel supported nor does he/she give support (selfish position)	- Tries to find within him/herself adjustment situations of overcoming the demands of the caregiver's role - Centred in his/her own framework of the situation and not in the patient's problems - Creates interpretative settings for the patient's experiences, behaving according with it - Incisive posture which can lead to communicational blockage - Alien to informational resources and environmental support - Low levels of emotional and social support lead to more baleful effects of this role	- Posture of one who detains knowledge - Decides according to what he/she believes to be the most correct (doesn't rely in other opinions) - Doesn't favour an informative and communicational environment between systems - Very directive posture

In the fourth position (Table 4), one observes that people, having found new normalization strategies, besides feeling well with themselves, undertake altruistic behaviours, with sacrifice and bounty towards others (Agra, 1997, 2001; Guerra, 1998). The subject refuses to restrict him/herself to his/her own animal fatality and to social solidarity, trying proactively from him/herself and the environment, to reconstruct his own reality from the diagnosis and course of the disease. One can find the order (autopoiesis) thorough out the crisis and suffering (Agra, 1990, 2001).

Table 4. Comparison of the intervenients at teleological level and projective position

Patient	Informal Caregiver	Formal Caregiver
- Disease as an opportunity of development, maturation and evolution - Maximization of personal, social, institutional and family resources - Implements diverse and appropriated coping strategies to face the disease - Frees himself from a series of constraints, recreating, re-organizing and giving a new meaning to the reality of the disease - Feelings of satisfaction and happiness - Positive integration of a negative experience	- Copes with a distress situation with tranquillity and as a growth opportunity - Ability to manage and find a balance for personal and environmental resources - Maintains the enjoyable activities at the same time that he/she cares for a patient - Capacity to ask for help - Implements appropriated strategies to solve personal and patient's problems - Strengthening of the caregiver-patient and patient-community relationship - The person is open to communication, attentive to him/herself and to the others and with initiative to re-establish homeostasis	- Professional that invests in the patient-doctor relationship - Sees the quality of the therapeutic relationship as being intrinsically connected to the established technical and communicative-informational relationship - Takes into account his own beliefs and emotions, the patient as a systemic and complex reality and the interactions that both establish with the environment - Capacity to construct for himself and for the patient a setting which is less fatalist and more multi-causal and multi-determined Capacity to cope effectively and constructively with the aspects that emerge during the disease confrontation process

By the fact that the action of caregiving is, by definition, an act that occurs in a social and relational context, we have tried below (Table 5) to expose a possible and idiosyncratic interpretation of what could result from the interaction between the two principal systems involved (Oliveira, Queirós & Guerra, 2007). We understand that, by the particularities of this relation, we can conceive an evolution that goes from the fatalistic acceptance by the caregiver and by the patient, to an autopoietic and creative adaptability.

Table 5. Levels and positions according to the kind of relationship established between caregiver and patient

		Caregiver (C)			
	Level	Ontological	Deontological	Logical	Autopoietical
Patient (P) Ontological		- P e C: Both believe that "There's nothing to be done". ↳ Fatalistic acceptance (chaos in both systems)	- P: "There's nothing to be done". - C: "With other's help something may improve". ↳ External expectation	- P: "There's nothing to be done". - C: "Only I can do something to improve the situation". ↳ Accountable isolation (the caregiver is alone in his own fight)	- P: "There's nothing to be done". - C: "With my personal resources, with you and with the environment this experience will be positively over come". ↳ Direct Convincement
Deontological		- P: "I put myself in others hands". - C: "There's nothing to be done". ↳ Hopelessness	- P: "I put myself in others hands". - C: "With other's help something may improve". ↳ Heteronomic hope	- P: "I put myself in others hands". - C: "Only I can do something to improve the situation". ↳ Limitative help	- P: "I put myself in others hands" - C: "With my personal resources, with you and with the environment this experience will be positively over come". ↳ Involvement stimulation
Logical		- P: "Only I can do something for myself". - C: "There's nothing to be done". ↳ Accountable isolation	- P: "Only I can do something for myself". - C: "With other's help something may improve". ↳ Relational conflictuality	- P: "Only I can do something for myself". - C: "Only I can do something to improve the situation". ↳ Conflictuous antagonism	- P: "Only I can do something for myself". - C: "With my personal resources, with you and with the environment this experience will be positively over come". ↳ Involvement descentration
Autopoietical		- P: "With my personal resources, with you and with the environment this experience will be positively over come". - C: "There's nothing to be done". ↳ Directed convincement	- P: "With my personal resources, with you and with the environment this experience will be positively over come". - C: "With other's help something may improve". ↳ Collaborative appeal	- P: "With my personal resources, with you and with the environment this experience will be positively over come". - C: "Only I can do something to improve the situation". ↳ Integrated concordance or inter-system disparity	- P e C: both believe in an adjusted re-construction and recreation of themselves, others and the world – happiness and well-being emerging from the disorder. ↳ Autopoietic Adjustment

CONCLUSIONS

From the bibliographical analysis and the "Autopoietic Subject Theory" application we can extract the following conclusions:
– Caregiving as an intrinsically human act only exists in a relational context between caregiver-patient.
– The concept is fundamentally approached in a practical and action domain contextualization perspective, as opposed to a purely theoretical conceptualization.
– Recent conceptualization of the health care professionals as caregivers, having not only technical and standardize obligations but also the duty of implementing humanized interventions.
– The framing of the patients, formal caregivers and informal caregivers in the "Autopoietic Subject Theory", allows the characterization of each one according to four distinct positions and levels.
– The interaction between caregivers and patients, and their respective positions and levels, generate different relational environments.
– In potentially disturbing events, the intervention may promote a dependent compromised caring relationship between two persons, in which autopoiesis and biopsychosocial adjustment lead to an increment in the well-being of both patient and caregiver.

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