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**ARTIGO DE REFLEXÃO**

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**FOR A COMPREHENSIVE APPROACH OF FAMILY CARE EXPERIENCE**

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**ABSTRACT**

This essay was based on the experience of the authors in the development of research in health and nursing whose central theme is family care experience, which is addressed by means of a comprehensive approach. In the development of this essay we seek to thematize how such approach flows in the research in a way which captures the shapes and outline of the fluid and dynamic reality that are the experiences of the daily human life, outlined in this comprehensive approach and, with privilege, in the History of Life; and the aesthetic and ethic dimensions. In the capture through the researcher's sensitive and empathetic eye toward the other (research participant), we realize the people and their families 'say yes to life', even in the face of the most difficult situations such as the illness; in a perspective of the now, people take care of life, in life and for life, trying to be close to the potentials that present themselves in the 'here and now', not permitting that the nearest possibility of finiteness be the deadly horizon that would annul this care. We understand that the comprehensive approach, by sensitively leaning on localized and personalized situations of illness and care, can support us in comprehending the permanence, transcendence, and universality of human suffering.

**Keywords:** Qualitative Research. Nursing Research. Family.

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**INTRODUCTION**

This essay was based on our experience during the development of studies and matrix research in health and nursing, with the family experience of care as the central theme. We are linked to the Brazilian public higher education institution at Undergraduate and Postgraduate levels in Nursing. These studies are conducted with comprehensive approach, allowing us to grasp the complexities in the daily life of families, with emphasis and intensifications in certain events that are integrated in the whole of living of each family member. Among these events, the focus of our studies has been the experience of illness involving, as a rule, some family members. Although the fact of falling ill has a central position within the whole of life, it does not stand out from the other things by which people go through, since it affects the other dimensions of life and every family member differently as they engage with care.

In the study development, we aimed to show how the comprehensive approach is drawn in the research, by using the History of Life to

apprehend the emphasis and contours of the familiar experience of care. Hence, we demonstrated our way of producing knowledge, and the first part presented the understanding of comprehensive approach as a creative way of researching, with distance from the research as an alignment of methods, strategies and techniques. The 'method' adopted consists in 'a referral'<sup>(1)</sup>, where the activation of 'open reason' allows to trace guiding elements, in order to apprehend the emphasis and contours of the fluid and dynamic reality of human everyday experience. In the second part, we discussed about possibilities of sensitive apprehension of the family experience of care, guided by the comprehensive approach and the History of Life, based on our experience over the past decade in coordinating matrix researches of the Research Group in Nursing, Health and Citizenship - GPESC (Brazil). We ended the study with some considerations about the ethical and aesthetic dimensions of the study with comprehensive approach in health.

**Comprehensive approach is drawn in the research**

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Understanding the life experience of people is an ideal, in other words, an aim as image-objective. However, this understanding is always a partial, localized and transient form of knowing the other.

What will be our perspective while drafting and conducting the study? Certainly, the understanding cannot be a totalitarian idea that is finished or reached through a thesis. Based on this premise, we adopted the comprehensive approach as the position or posture towards the other, towards life, and the ways of giving oneself for knowing all this. Such posture aligns with the understanding of human beings in the impermanence and incompleteness of their forms, sure about the uncertain and temporary experience that form their existence conditions. Thus, there was no concern in naming ourselves, neither what we produced with any labels, but efforts to describe the *forms* in its essential characteristics.

Giving ourselves for knowing, within the structure of a more open reason, in this *modus operandi*, we try to emphasize a multitude of subtle reasons capable, at the same time, of realizing the inner strength of each phenomenon and its necessary conjunction with the whole<sup>(1)</sup>.

We focus on the presentation of 'how' things pass and happen, on a detailed description of situations experienced by people, without any ambition of draining its multiple meanings and dimensions. We understand it is not a limitation of thinking, but a broadening of thought to understand in depth what constitutes the specificity of each situation and each experience, helping to arouse the vital effervescence. And, in this movement, sometimes it is necessary to give up our certainties in favor of the reality inflows<sup>(2)</sup>.

Therefore, we approach what can be called 'intuitive knowledge', made from a view from within - *intuire*<sup>(1)</sup>. This comprehensive posture is a position of the researcher in the world and in face of what happens, placing him/her 'in relation' to people and with what 'happens' to them. This way, there is a 'compassion', i.e., 'living with' the other, sharing with him/her the recollection of their experiences, seeking to grasp the meanings and feelings emanating from there. By affirming this proximity perspective of and with the other, we elected some essential

principles that guide the study by inquiring ourselves: understanding for what? Thus, we seek fidelity to the principle of putting the other - person and family - as central in the care and putting ourselves involved with this care, necessarily giving new meaning to health knowledge and practices to make them more effective in their lives. This attitude towards the other enables approximation and recognition of the personal and family experience of illness and care, highlighting the developments it generates and the potential of professional practices to support the other in this experience<sup>(3)</sup>.

In this empathetic movement with the other we keep a certain distance; not so small to lead us to lose the context of his/her experience, and not so large to stop us from knowing the ins and outs of this unique human experience.

Such posture supports the understanding of the study as a movement, as a dashed line that is gradually reworked from an initial design, referring to other levels of appreciation and understanding of the human experience. Thus, an initial intuition of the situation experienced by people in more dimmed contours becomes clearer after every meeting, by bringing new light as people tell their experiences, and because of our apprehension of the text and context of their experiences.

In the sensitive conduct of the study, we are guided by the author's alert that this is a rather serious and difficult process that should not be confused with rigor, which is always necessary, and turn it into stiffness, which is the opposite of intelligence and invention; bringing his irony: "Deliver ye from methodological watchdogs"<sup>(4:26)</sup>. The author also draws attention to the fact that constructing the research object is not an 'inaugural theoretical act'<sup>(4)</sup>, a plan that is drawn in advance.

For us, the research design 'unfolds' gradually, in movements of approximation and emphasis, i.e., where certain emphasis is assigned to the complex web of human experience without the ambition of totality, because incompleteness is its form of existence. This encounter of two subjects involves the sensitivity of the researcher to recognize the other, and the other, in turn, by opening up and revealing the importance of events in his/her life. The tone of telling, the scansion of time, and the

senses are, among others, central to the design of each study subject - built in the experiment, not a priori.

This effort of impressing ourselves with the experience of the other to delineate its contours and emphasis brings us the idea of the impressionist painting as the understanding of our way of researching and the research as art creation. On this theme, author<sup>(5)</sup> argues that the impressionist painter seeks to escape the enclosure of ready-made formulas, realizing the ambiance that comprises his surroundings. In this sense, "the intellectual impressionism also seeks the simplicity of everyday life, emphasizing its changing aspects; and in so doing, highlights the feeling of dream, peculiar of the inescapable passing of hours and days of which the daily life is impregnated"<sup>(5:28)</sup>.

Therefore, in the comprehensive approach of people's experience, it is not about 'placing' the elements that comprise a certain object of study in a given order, as if there were 'vanishing points' to function as the limit, because the design would resemble a 'still life' painting. The object is the end point of the study when it is embodied in the human experience, always local, particular, substantivized, expressing its emphasis and senses. Thus, in the verbalization of the own emphasis, the object is revealed for the researchers, shaping itself to our eyes.

### **Comprehensive approach of the family experience of care**

In understanding the family experience of care and illness we have employed the History of Life<sup>(6-7)</sup> with privilege. The ill person and his family members are invited to tell us about the 'whole of their lives', what they do from their own logic, both in situations they have lived, as in the time plot. Certainly, the reality of experiential time is different from or mismatches the time of cold hours - the physical time that is independent from us. In this recollection of what every individual lived, the narrative threads are conductors of the gradual deepening in what seems relevant to the person and of most interest to the focus of the study.

In our studies, the conception of History of Life is made intrinsically in the understanding of people's experiences because the events they recall are full of meaning, since this is the 'what happens' to them, what they go through and

touches them<sup>(8)</sup>. Furthermore, what people narrate, although may not be the actual lived experience, is rich in interpretative elaboration of the lived events that are recalled. Memory is the force linking the train of thought of the life interpreted in the present, and is made with future anticipations. Therefore, it is necessary to have patience while the person unfolds the narrative events of his/her history, since the memory is (un)certain in its own way. It is also required that other logics are followed in the unraveling of events, in an integrative process of the lived routine, connected to what somehow has touched and penetrated the affective memory<sup>(5)</sup>.

We dedicated ourselves to study the 'tell oneself' of such experiences, and took time to 'overthink' and 'chew' the meanings people attribute to them. By linking the apprehension of these concepts, it is possible to understand how our professional practices in health affect their lives.

The stimulation to 'tell oneself' is given by the researcher from the own narrative threads woven by each respondent<sup>(6)</sup>; thus, the deepening of the interview is consolidated through various meetings. Over these encounters, we produce 'conglomerates' of the perspectives that most call our attention among all the narratives, in line with the draft or dashed line initially planned for the study, gradually designing it as we advance in research.

Therefore, the experience of care and illness remains integrated with what was lived as a whole, but gains nuances of a *composé* from the 'tones' given to this experience by each family member interviewed, showing us how every individual is affected and affects the family experience. There is no concern with confrontation of the narratives, but with the composition in the family life network, showing how each family member feels the experience of illness and the need to care for the ill person, emphasizing the impacts of this shared experience.

In the effort to apprehend the family experience, we value our own perception ability, since the world where people inhabit is made of shapes, sounds, smells, textures, architecture, objects, movements, relationships - everything that we can apprehend, impressing our senses

and intuitions. Hence, this world is full of (un)speakables and (in)visibles, and stands as a field of possibilities to the observer/researcher, requiring sensitive means of apprehension in research. As an example, the observation, before being an objective and systematic act, comprises an 'observation with attention' through 'eyes to see'<sup>(9)</sup>, because we believe that what we see is a tributary of the presentation, of showing the observable<sup>(1)</sup>, given that things are not given a priori, but made present to a sensitive eye.

We work with detailed descriptions in order to value our perception, generating mental images from what people tell or by our observation. Our imaginary, in turn, will produce the reading of these images, seeking to return, whenever possible, the fluidity and movement of what people have lived.

We understand that the images seek to be the imagetic expression of what was lived in its 'coagulated/aprehended form, in another way of saying it that impresses the sensitivity. In the presentation of his work called 'Complete Poetry', author<sup>(10:7)</sup> tells us that "This merger with nature took my freedom of thought. I wanted egrets to dream about me. I wanted the words chirping me. So I started to do verbal sketches of images. I nailed it". The idea of seeking to produce 'verbal sketches of images' was dear to us, the same way as producing images from what is told. Thus, we also began to prepare images of different modalities - drawings, diagrams, maps, genograms, among others - that could give some order and understanding to what we describe of the histories of life. Based on these arguments, we use the imagetic production in our studies as a powerful methodological and interpretative resource.

We remember what author<sup>(11)</sup> calls 'imaginal perspective', taking the image as a 'mesocosm', a world in-between the macro and the microcosm, between the universal and the concrete, between the general and the particular. Therefore, the image has the ability to illustrate, name and describe, highlighting the internal reason that animates each thing. The author also states that the image may favor "access to a kind of direct knowledge, knowledge from sharing, pooling of ideas, of course, but also from experiences, lifestyles and ways of being"<sup>(11:102)</sup>.

We work the image in this perspective - as a way of saying in coherence with our study themes by producing identification in those that approximate of it, since they are also imagetic beings. For doing so, the researcher must be an 'interested presence' in relation to what he/she observes, learns, describes and interprets. He/She is also a 'relations builder', since by empathizing with the other, i.e., establishing an affective identification he/she weaves and narrows this relation, seeking to penetrate the senses of living/feeling of the other. For this reason, the researcher 'puts into perspective' the narrative, contextualizing it in the whole of the person's experience<sup>(2)</sup>. For that purpose, it is necessary to employ the senses and the intuition in full, carefully and openly, without preconceptions, i.e. without pre-defined guidance. Note that the investigative look is built by 'seeing' what was 'used/trained' to value.

The apprehension of the other's experience is done by the composition of different sensitive ways of perceiving - complementary, integrative, of reconnection; therefore, the in-depth interview, the observation field and image production are a set of methodological possibilities for dealing with the complexity of situations presented to us by the people when narrating their living. It differs from triangulation or cross-checking because these employ different means to realize the reality, not rarely aiming at 'confrontation of data', or its 'confirmation'.

Therefore, we seek to model the 'form' of each study by defining the design when framing the experience of illness and care of each family. In relation to the frame<sup>(12)</sup>, author reminds us of its essential character in painting, which is to value what it limits. The same happens when we frame the living of the ill person and his/her family, by seeking to emphasize the meanings attributed to each situation, the ways of leading the life of each family member and family, and the relations and ambiances that comprise everyday life, among others. Although this movement produces limitations of what it isolates, it also allows the researcher to have a broader understanding of what was emphasized by him/her, since keeping a certain distance enables the ethical and aesthetic apprehension of this experience.

For a reflection about the different ways of understanding what people have lived, there is the interesting kaleidoscope metaphor, which puts us in a relationship with something of almost infinite potentiality of producing shapes, composing them in a different way with every light and subtle movement. It is the sensitivity and subtlety of the person who moves the kaleidoscope that 'form a pattern'. The same happens in studies of comprehensive approach, because the way of being present in face of the other, being sensitive to their talk, and having eyes to see what is present in the situation during the meetings will bring the elements to compose the way of understanding a certain dimension of the experience lived.

### **The aesthetic and ethical dimensions of the comprehensive approach**

By conceiving the research as 'creative work', or as 'work of art'<sup>(13)</sup> taken from an initial draft that is designed throughout the research process, we assume its aesthetic and creative dimensions. In this movement, emphasizing the 'out croppings' previously present in the draft without neglecting the 'waste', but composing them into an organic whole, approximates them of the impressionist painting. Although this art is a fragment of the living dynamics 'frozen' in time, by pure magic it 'gives life' to what would be inert otherwise. This magic is in the very composition of the painting, its creation method or its conception, in the colors and the feelings of the artist when capturing the scene seen or imagined by him/her. Indeed, this is the other part of the magic – 'the eye/heart' of the artist, by capturing what is visible, gives it other dimensions that would be invisible otherwise. Similarly, in the comprehensive approach adopted, we sought to present the nuances of the experience lived, with its colors, movement and own light<sup>(13)</sup>.

The ethical dimension is embodied in our study when we assume the deep respect for the human dimension that supports the research, both from the experience of the ill person and family, as from the researcher's experience, mutually affecting each other and defining the own design of the search. Thus, an ethical attitude of the investigator is established throughout the study, formalized in the ethics

approval for research with human subjects<sup>(14)</sup>, but that goes far beyond it.

The comprehensive approach itself, by assuming the History of Life as a privileged way of apprehending the experiences of individuals and families, implies someone who 'tells him/herself' to the other and to him/herself, and someone who listens to the experience of the other and colors it, giving emphasis from elements of one's own experience. Thus the research is a 'living-with', a 'shared experience', because although the researcher has not lived with the interviewed person, what the person tells the researcher, when telling it, recalls what was lived and brings to the 'here/now' this recollection, which is then, contemporary to both.

On this matter, author<sup>(5)</sup> points out the return of sensitivity, more lived than thought, which takes on the idea of creativity of existence. In this notion of creation of life and life as a work of art, aesthetics is the sharing of emotions, weaving the lace, (re)connecting, another way of saying the ethics of existence.

### **FINAL CONSIDERATIONS**

The centrality of our studies is in the apprehension of the experience of illness and care for people and family, which have allowed our understanding of how this experience affects the life of every person and the own production of care, in multivariate reverberations that are difficult to apprehend if not by the sensitive and empathic look of the researcher towards the other (study participant). In this expanded understanding, we realize that people and their families 'say yes to life' even in the face of difficult circumstances like illness. In a perspective of the present, people take care of life, in life and for life, seeking to be well within the potentialities available in the here and now, not allowing the possibility of a closer finitude to be the deadly horizon that would nullify this care.

From this perspective, we ask: how and to what extent our professional practices in health can support these people in their potentials of care, aiming to make them more effective in diminishing the suffering?

We believe the comprehensive approach, by sensitively addressing the localized and personal situations of illness and care, far from providing just the geo-political and social constituency of

its event, can support us in understanding the permanence, transcendence and universality of human suffering; and can therefore, be empathically understood by other humans.

## POR UMA ABORDAGEM COMPREENSIVA DA EXPERIÊNCIA FAMILIAR DE CUIDADO

### RESUMO

Este ensaio foi embasado na vivência das autoras durante pesquisas na área da saúde e enfermagem com o tema central da experiência familiar de cuidado. Ambas têm aproximação com o tema pela abordagem compreensiva. No desenvolvimento do ensaio procurou-se tematizar como tal abordagem desenha-se na pesquisa para apreender os relevos e contornos da realidade fluida e dinâmica da experiência cotidiana humana, pautados na abordagem compreensiva e, privilegiadamente, na História de Vida; e nas dimensões estética e ética desta abordagem. Na apreensão pelo olhar sensível e empático do pesquisador em direção ao outro (participante da pesquisa), ficou claro que as pessoas e suas famílias 'dizem sim à vida', mesmo enfrentando situações mais difíceis como o adoecimento. Em uma perspectiva do presente, as pessoas cuidam da vida, na vida e para a vida, buscando estar bem dentro das potencialidades no 'aqui e agora', sem permitir que a possibilidade da finitude mais próxima seja o horizonte mortífero que anularia esse cuidado. Ao se debruçar de modo sensível sobre situações localizadas e pessoalizadas de adoecimento e cuidado, a abordagem compreensiva pode auxiliar a compreensão da permanência, transcendência e universalidade do sofrimento humano.

**Palavras-chave:** Pesquisa Qualitativa. Pesquisa em Enfermagem. Família.

## PARA UN ENFOQUE COMPRENSIVO DE LA EXPERIENCIA FAMILIAR DE CUIDADO

### RESUMEN

Este ensayo se basó en la vivencia de las autoras en el desarrollo de investigaciones en el área de la salud y enfermería que tienen como tema central la experiencia familiar de cuidado, de la cual tienen aproximación mediante el enfoque comprensivo. En el desarrollo del ensayo se buscó tematizar cómo tal enfoque se esboza en la investigación de modo a reflexionar los relieves y contornos de la realidad fluida y dinámica de la experiencia cotidiana humana, basados en el enfoque comprensivo y, privilegiadamente, en la Historia de Vida; y la dimensión estética y ética de este enfoque. En la aprehensión por el aspecto sensible y empático del investigador en dirección al otro -participante de la investigación- notamos que las personas y sus familias 'dicen sí a la vida', aunque enfrentando las situaciones más difíciles, tal como la enfermedad. En una perspectiva del presente, las personas cuidan de la vida, en la vida y para la vida, buscando estar bien dentro de las potencialidades que se presentan en el 'aquí y ahora', no permitiendo que la posibilidad de la finitud más próxima sea el horizonte mortífero que anularía este cuidado. Entendimos que el enfoque comprensivo, al volcarse, de modo sensible, sobre situaciones localizadas y personalizadas de enfermedad y cuidado, puede favorecernos en la comprensión de la permanencia, transcendencia y universalidad del sufrimiento humano.

**Palabras clave:** Investigación Cualitativa. Investigación em Enfermería. Família.

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