

Education, Ethics and Health: Learning to Care from the Optics of Oncological Patients

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Abstract: The present study is part of an educational sciences PhD program and aims to evaluate the educational process that can result from the suffering process experienced by oncological patients. The main purposes of the study are: build up in the oncological patients the capacity to acquire knowledge due to their suffering experience related to the disease; and be able to transfer the obtained knowledge to formal and informal caregivers. We found that patients do not always know their ability to manage their difficulties about the disease and its real care needs, a situation which results in a lack of knowledge on the part of formal caregivers, about the experience that patients have of their disease, with order consequences technical and ethical. In this paper, the salutogenic perspective Antonovsky; and the ethics of care in the health context are the theoretical assumptions. We consider that each oncological patient has an educator status, as he/she can teach and is, more over, the one who can teach not only the possible direction of the disease, but the specifics of the illness; these specifics as the possible direction of the disease, are inextricably linked to what Antonovsky appointed as internal sense of coherence, for which evaluation he built the SOC questionnaire. For their turn, the ethics of care, according to Kemp and Rendtorff, defines four ethical principles in the context of health and medical research: autonomy, dignity, integrity and vulnerability. These principles are inseparable and must be understood in a general framework of solidarity and responsibility.

Key words: education, health, SOC, oncological patients

1. Introduction

This communication is part of a doctoral Project in education sciences at the Trás-os-Montes e Alto Douro University (Portugal). The theme of this work is the education in the suffering of oncological patients in a perspective of education throughout the life and whose purposes are: (1) to promote in the oncology patients the capacity to withdraw learning from their suffering experience by the illness and (2) to transfer this knowledge to

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the learning of care by formal and informal caregivers.

The oncological patient — each oncological patient — has something to teach, because the fact of being alive refers to experiences lived in his daily life which can serve as learning to be transferred to others, whether they are also patients or caregivers. The motivation for the study comes from the empirical observation that patients are not always aware of their capacity to manage their difficulties about the illness and its real needs of care. This situation results in a lack of awareness among the formal caregivers about the experience that the patients have about their disease with technical and ethical consequences. In theoretical terms the work sought to be based on the salutogenic perspective purposed by Aaron Antonovsky: as well as in the ethics of caring in the context of health. We consider that each oncological patient has an educator status because he can teach and he is, moreover, who can teach not only the possible meaning of the illness but also the specificities of the disease: these specificities as the possible meaning of the disease are inseparable from what Antonovsky (1978) has designated internal sense of coherence, for which he constructed the SOC questionnaire. This article sought to focus in the evaluation of the Internal Sense of Coherence of individuals who have been affected by cancer (whether or not they are cured) in order to identify their capacity to cope with this stressful situation. Regarding the ethics of caring, we rely on Kemp and Rendtorff (2008), Noddings (2003), Torralba I. Roselló (1998) who sought to understand caring as ethical principles.

Specifically, it was sought to know/understand the extent to which the interviewed (under treatment or cured) were able to deal with the illness in order to understand it, manage it and give meaning to this coping situation, analyzing the Internal Sense of Coherence by means of the SOC questionnaire.

2. Methodology

In this article we work with the methodology of SOC — Internal Sense of Coherence, where it was used the SOC Scale (Internal Sense of Coherence) proposed by Aaron Antonovsky, following its validation to the Brazilian Portuguese presented by Dantas (2007). “The instrument proposed by the author to evaluate the construct comprises 29 items that evaluate the orientation of the individual on various issues related to his life” (Dantas, 2007, p. 1). The aim of this study was to test the metric properties (validity and reliability) of the participants based on the Antonovsky’s Sense of Coherence Questionnaire (SOC).

Twelve (12) previously selected patients (who were or were not receiving treatment, cured or monitored) were interviewed. Participants were from both sexes, any degree of education, age, race or color but fulfilling the following criteria: to be an oncological patient; to have reconfigured his life after the diagnostic and living with cancer; to be indicated by an association, doctor or hospital accompanying him; be literate; to reside in Minas Gerais, Brazil; to feel like sharing his experience with other people. The questionnaires were delivered and answered without the interference of the researcher and the interviewee had to interpret the meaning of the questions. The period of data collection occurred between October 2015 and March 2016. For socio-demographic and clinical characterization were inserted questions regarding: age, sex, instruction degree, profession and type of cancer.

After the collection of the questionnaires the treatment of the information began. The data collected were coded, eliminating all personal information associated with them. The data were processed and analyzed by the Excell 2000 program. The variables were analyzed in a descriptive way, being calculated the mean and the standard deviation for numerical variables.

Participant selection procedures and SOC questions were previously submitted to the CEP — Comitê de Ética em Pesquisa da Universidade FUMEC de Belo Horizonte/MG (Ethics Research Committee of the FUMEC University of Belo Horizonte/MG) and to the Comissão Ética da Universidade Trás-Os-Montes e Alto Douro (UTAD) (Ethics Commission of the Trás-Os-Montes e Alto Douro University) for analysis and approval.

3. Results

3.1 Socio-demographic and Clinical Characterization of the Participants

In the present study 12 people agreed to participate, answering to the research questions. Among the 12 individuals that participated in the study, 8 (66.7%) were female and 4 (33.3%) were male. The mean age was 56.67 ± 11.7 (minimum 31 and maximum 75). All participants had formation in higher education and most of them were teachers. Four participants (33.3%) were in treatment phase of the disease when they participated in the research, 4 (33.3%) were under follow-up and 4 (33.3%) answered being cured. The main type of cancer related to the participants was the intestine (5), followed by breast (3). The data are shown in Table 2.

Table 2 Socio-Demographic and Clinical Data of the Study Participants

Participant	Sex	Age	Profession	Disease Condition	Cancer Type
1	M	66	Teacher/Doctor	Healed	Intestine, kidney and thyroid
2	M	57	Businessman/ Teacher	Healed	Intestine
3	F	58	Teacher/Geographer	In treatment	Breast
4	F	62	Housewife/Teaching	In treatment	Breast, lung, hair
5	F	54	Teacher	In treatment	Myeloma
6	F	45	Teacher/Pedagogue	In follow-up	Intestine
7	F	49	Teacher/Chemistry	In follow-up	Thyroid
8	F	54	Teacher/Architect	In follow-up	Stomach
9	F	31	Environmental Engineer	In follow-up	Skin
10	M	59	Teacher/Psychologist	Healed	Intestine
11	M	70	Teacher/Engineer	In treatment	Lymphoma
12	F	75	Psychologist	Healed	Breast

3.2 Descriptive Analyzes of Antonovsky's (SOC) Sense of Coherence Questionnaires

Anotonovsky's Sense of Coherence Questionnaire (SOC) is divided in three components: understanding (Nos. 1, 3, 5, 10, 12, 15, 17, 19, 21, 24 and 26), handling (management) (Nos. 2, 6, 9, 13, 18, 20, 23, 25, 27 and 29) and meaning (investment) (Nos. 1, 4, 7, 8, 11, 16, 22 and 28). Your descriptive analysis can be done by the sum total of answers obtained (interval 29 to 203) or by the average of the items (interval 1 to 7). The possible interval of total SOC score is ranged from 29 to 203, in this research the interval ranged from 107 to 127. The results are presented in table 3. Regarding the value of the total SOC score it was possible to observe a median from 150 and a mean of 147.08 ± 16.30 . This result is shown above the median interval between 29 and 203 (116), that is, individuals have an Internal Sense of Coherence medium to high, which helped them to cope with stress situation they have been through or are passing through.

The item "meaning" was the one that presented the highest average for the participants of the study (5.77 ± 1.26), denoting the capacity of each one to perceive that life events make sense and therefore find reason to

invest in them their energy. On the other hand the item “understanding” was the one that showed the lowest mean (4.24±1.80) demonstrating that the interviewees can’t apprehend the internal and external stimuli as ordered, consistent, structured and clear information. The total mean of the 29 items that composed the questionnaire was 5.07±1.75 with a median of 5.

Table 3 Descriptive statistics of the Antonovsky’s Sense of Coherence Questionnaire (SOC) by Component and Total of Questions

Component	Median	Mean±SD
Understanding	5	4.24±1.80
Handling (management)	6	5.43±1.68
Meaning (investment)	6	5.77±1.26
Total of 29 items	5	5.07±1.75
Sum of 29 items	150	147.08±16.30

Regarding the analysis according to the questions of each component, for the “understanding” component the question of life in the future (question 17) was the one that presented the lowest mean score in the sample studied (3.08±1.56) while the related one to the positioning of life events (question 26) was the one that presented the highest score (Table 4). This demonstrates a change in understanding what is important, where the interviewees show more importance to the moment in which they are living, seeing problems as they are without fantasizing or creating expectations. However, the results in general show that this cognitive component has remained stable, sometimes demonstrating that the individual has become more shaken or has felt more confident in facing the stimuli to which he was exposed.

Table 4 Descriptive statistics of the Antonovsky’s Sense of Coherence Questionnaire (SOC) in relation to the “Understanding” Component

Component-Understanding	Median	Mean±SD
1. When you talk to people do you have a feeling they don’t understand you?	4	4.33±1.37
3. Think of people with whom you have daily contact, in addition to those with whom you feel closest. How well do you know them?	5	4.83±1.34
5. Has it happened in the past that you surprised yourself with people you thought you knew well?	3.5	3.83±1.53
10. In the last 10 years, your life has been:	4.5	3.67±2.02
12. Have you the feeling of being in an unusual situation and not knowing what to do:	5.5	5.17±1.64
15. When you face a difficult problem, the choice of a solution is:	5	4.5±2.02
17. You life will be in the future:	3	3.08±1.56
19. Do you have conflicting ideas or feelings?	3	3.5±1.98
21. Have you ever had feelings inside you that you would rather not feel?	3	3.58±2.12
24. Did you ever feel that you didn’t know exactly what was about to happen?	5	4.5±1.51
26. When something happens, you usually:	6	5.67±1.30

For the “handling” (management) component that refers to the perception that each one has that the resources are available and are suitable to respond to the requirements needed by the stimulus situation, the results show that questions 9 to 13 were those that presented higher scores (6.33±0.65 and 6.33±0.78), while the question 6 was the one with the lowest score mean (3.42±1.73) (Table 5). Regarding to the component “meaning” (investment capacity) that refers to the amplitude in which the person feels that life makes sense emotionally that is worth investing energy in problems and needs, all the questions showed values above five, indicating a high sense of

coherence in regards to this component (Table 6). It's worth emphasizing that interpretation must be made according to the response options of each question and with its positive or negative direction but high values always indicate a strong sense of coherence.

Table 5 Descriptive Statistics of the Antonovsky's Sense of Coherence Questionnaire (SOC) in Relation to the "Handling" Component

Component-Handling	Median	Mean±SD
2. In the past when you had to do something that depended on the cooperation of others, you had the feeling that:	5	4.92±1.98
6. Has it ever happened to people you were counting on to disappoint you?	3	3.42±1.73
9. You have the feeling of being wronged:	6	6.33±0.65
13. What best describes how you see life:	6.5	6.33±0.78
18. When something unpleasant happened in the past, your tendency was:	6	5.5±1.69
20. When you do something that gives you a good feeling:	7	6.25±1.14
23. Do you think there will always be people you can count on in the future?	7	6.08±1.38
25. Many people — even those with a strong character — sometimes feel like "losers" in certain situations. How often have you felt like this in the past?	4	3.83±1.40
27. When you think about the difficulties you have faced in important aspects of your life, you have the feeling that:	6.5	6.25±0.97
29. How often do you have the feeling that you can't keep the situation under control?	5.5	5.33±1.56

Table 6 Descriptive Statistics of the Antonovsky's Sense of Coherence Questionnaire (SOC) Related to the "Meaning" Component

Component-Meaning	Median	Mean±SD
4. You have the feeling that you really do not care what is going on around you:	6	6.0±1.13
7. Life for you is:	5.5	5.25±1.86
8. So far his life has been:	6	6.33±0.65
11. Most of the things you plan to do in the future will probably be:	5	5.17±1.19
14. When you think about life, you often:	7	5.92±1.73
16. Doing things from day to day is:	5.5	5.42±1.24
22. Do you feel that your life in the future will be:	6	6±0.85
28. How often do you get the feeling that the things you do daily in your life have little meaning?	6	6.08±0.67

3.3 Results Obtained by Comparing Different Groups

The results obtained by the comparing the means between the groups are presented in Table 8. Regarding subject's ages, no difference was observed between the means presented for individuals with less than 60 years (143.38±18.67), when compared to those with the same age or superior to 60 years (154.5±7.14). Even considering that age is a delimiting element for the man the interviewees are in the adult and elderly phase what justifies means so close. The fact that everyone is over 30 years shows according to Antonovsky its complete establishment. It was observed that even those over 60 years presented an active professional life what doesn't put them at the margins of society, influencing their SOC.

Table 8 Means of the Total SOC Values according to the Different Groups

Variable	N	Mean±SD
<i>Age</i>		
< 60	8	143.38±18.67
≥ 60	4	154.5±7.14
<i>Sex</i>		
M	4	135.5±20.74
F	8	152.88±10.87
<i>Disease state</i>		
Healed	4	139.25±25.13
Follow-up	4	146±8.76
Treatment	4	156±8.76

Figure 1 shows the distribution of measurements for these two groups. For sex of the participants was observed a tendency of higher mean SOC scores in women (152.88±10.87) demonstrating that they felt significantly less stressed with the disease, when compared to the men (135.5±20.74) with a value of P = 0.08 (Figure 2). According to Antonovsky the individual's sex, as well as, age, degree of education and transculturality "is not indifferent to the constitution of the SOC" (Antonovsky, 1986, p. 91). According to Nunes (1999) several studies in this sense showed that when it comes to men and women the latter are safer when faced with stressors, presenting coping resources.

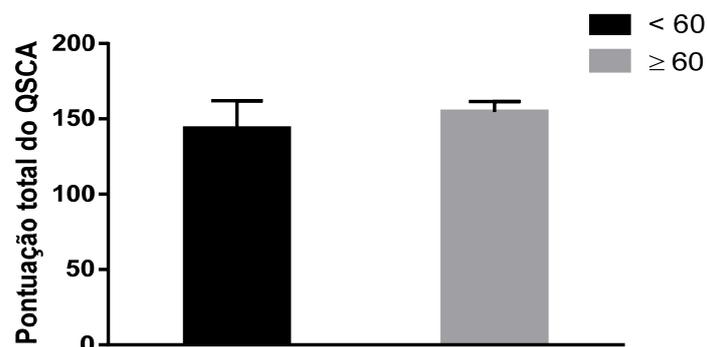


Figure 1 Measurement of the Total Coherence Sense Obtained by the SOC in relation to the Age of the Participants

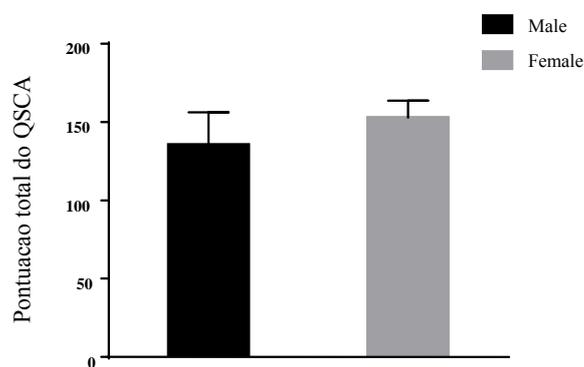


Figure 2 Measurement of the Total Coherence Sense Obtained by the SOC in Relation to the Sex of the Participants

Although higher mean values were observed for the subjects undergoing treatment of the disease no significant differences were observed related to the disease state in the participants (Figure 3).

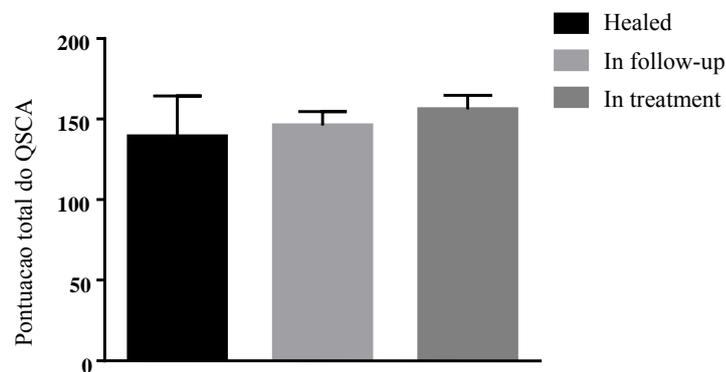


Figure 3 Measurement of the Total Sense Obtained by the SOC in relation to the Disease State

4. Conclusions

Antonovsky's main thesis turns to the fact that a strong SOC is a decisive factor in dealing successfully with ubiquitous stressful situations and thus for maintaining health (Antonovsky, 1987). For him the SOC is like "a stable characteristic" that isn't formed just by individual factors but also by historical, social and cultural conditions (Bengel, Strittmatter & Rebecka, 1999, p. 72).

The Internal Sense of Coherence and the mental health of the individual are closely linked demonstrating that the SOC can influence the perception of a stressful condition by an individual. In the present case, the interviewees showed a coping capacity in some cases, since when they presented high SOC they showed that the problem with the disease led them to seek a better comprehension (meaning) of the problem in order to control it and seeing it like a challenge to be faced and not a burden. According to Antonovsky (1987) when something undesirable and unexpected (like this disease) arises, those with a high SOC are sure to be able to cope it. In the present case men showed lower values of SOC than women, demonstrating that they have fewer resources for the confrontation (management capacity). For Antonovsky (1987) this condition turns not only to the abilities of the individual but to the help and influence obtained by other people or institutions.

However, in relation to the state of the disease the individuals demonstrated to remain balanced, that is, motivated to analyze the problem, seeking resources and strategies more suitable to face the disease. We can infer that the interviewees generally saw the diagnosis as a challenge but kept their vision positive to the future, believing that it was possible to face the disease through some form of control.

To this end the support (care) of the family (emotional component), institutions, as well as other people who may have contact become a fundamental point for facing the illness. With this study we could verify that the oncological disease, as a limiting situation, generates stress in the life of the patients; that some people grow, evolve, learn with the suffering that the oncological disease brought to them and that is susceptible to identification by the way these people face it, regardless of the cure. It is therefore a process of learning and education of the patients themselves, at the same time that it has implications in the caring process and thus is also relevant for the learning of the training caregivers. In fact, we can anticipate that if we identify the conditions that contribute to these people to learn in the disease we can try to create similar conditions in other patients so as to provide them with a similar process.

References

- Ahmed N., Lobchuk M., Hunter W. M., Johnston P., Nugent Z. and Sharma A. (2015). "Perceptions and preferences of patients with terminal lung cancer and family caregivers about DNR", *Cureus*, Vol. 7, No. 5.
- Antonovsky A. and Bernstein J. (1986). "Pathogenesis and salutogenesis in war and other crisis: Who studies the successful copier", in: Milgram N. A. (Ed.), *Stress and Coping in Time of War: Generalizations from the Israeli Experience*, New York: Brunner/Mazel, pp. 52–65.
- Antonovsky A. (1987). *Unravelling The Mystery of Health: How People Manage Stress and Stay Well*, San Francisco: Jossey-Bass.
- Antonovsky A. (1996). "The salutogenic model as a theory to guide health promotion", *Health Promotion International*, Vol. 1, pp. 13–17.
- Azevedo M. C. (2014). "Receber cuidados e ensinar a cuidar: lições de doentes crônicos aos seus cuidadores", *Vila Real: UTAD*, p. 9.
- Bengel J., Strittmatter R. and Rebecka H. (1999). O que mantém as pessoas saudáveis? O estado atual da discussão e a relevância do modelo de saúde Salutogênico de Antonovsky, Colônia: Centro Federal de Educação em Saúde – FCHE.
- Cestari M. E. W. and Zago M. M. F. (2005). "A prevenção do câncer e a promoção da saúde: um desafio para o Século XXI", *Rev. Bras. Enfermagem*, Vol. 58, No. 2, pp. 218–221.
- Carrondo E. M. (2006). "Formação profissional de enfermeiros e desenvolvimento da criança: Contributo para um perfil centrado no Paradigma Salutogênico", doctor thesis, Minho: Universidade do Minho, p. 298.
- Dantas R. A. S. (2007). "Adaptação cultural e validação do questionário de senso de coerência de Antonovsky em uma amostra de pacientes cardíacos Brasileiros", Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto/USP, Tese de Livre Docência, Ribeirão Preto, p. 115.
- Eriksson M. and Lindström B. (2005). "Validity of antonovsky's sense of coherence scale: A systematic review", *J. Epidemiol Community Health*, Vol. 59, pp. 460–466.
- Folkman S. and Lazarus R. S. (1985). "If it changes it must be a process: Study of emotion and coping during three stages of a college examination", *Journal of Personality and Social Psychology*, Vol. 48, No. 1, pp. 150–170.
- Freire L.G. (1998). *Pedagogia da Autonomia: Saberes Necessários à Prática Educativa* (7th ed.), Rio de Janeiro: Paz e Terra.
- Freire P. (1997). *Pedagogia da Autonomia: Saberes Necessários à Prática Educativa*, São Paulo: Paz e Terra.
- Kemp P. and Rendtorff J. D. (2008). "The Barcelona declaration", *Synthesis Philosophica*, Vol. 46, No. 2, pp. 239–251.
- Lazarus R. Y. and Folkman S. (1986). *Estrés Y Procesos Cognitivos*, Barcelona: Martínez Roca.
- Maciel K. F. (2011). "O pensamento de Paulo Freire na trajetória da educação popular", *Revista Educação em Perspectiva*, Viçosa, Vol. 2, No. 2, pp. 326–344.
- Navarro M. F. (1999). "Educar para a saúde ou para a vida? Conceitos e fundamentos para novas práticas", in: J. Precioso et al. (orgs.), *Educação para a Saúde*, Braga: Departamento de Metodologias da Educação, Universidade do Minho, pp. 13–28.
- Noddings N. (2003). *Uma abordagem feminina à ética e à educação moral*, São Leopoldo: Unisinos (Trabalho original publicado em 1984).
- Noddings N. (2009). "The aims of education", in: D. J. Flinders & S. J. (Eds.), *The Curriculum Studies of Education* (3rd ed.), New York: Routledge, pp. 245–438.
- Nunes (1999). "O sentido de coerência: Operacionalização de um conceito que influencia a saúde mental e a qualidade de vida", Dissertação de mestrado, Universidade Nova de Lisboa, Lisboa, p. 83.
- Oliveira C. C. and Costa A. L. (2012). "Viver o estado terminal de um familiar: leitura salutogênica de resultados de um caso", *Saúde Soc.*, Vol. 21, No. 3, pp. 698–709.
- Oliveira C. C., Pellanda N., Boettcher D. and Reis A. (2012). *Aprendizagem e sofrimento: narrativas*, SCS: Santa Cruz do Sul, EDUNISC.
- Santos C. S. V. B. (2006). *Doença oncológica: representação, coping e qualidade de vida*, Coimbra: Formasau.
- Torralla i Roselló F. (2009). *Antropologia do cuidar*, Petrópolis: Ed. Vozes (Trabalho original publicado em 1998).