# Patterns of cancer-related internet searches: reactiveness; risks; the role of affect

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> **Abstract** The popularization of ICTs and the availability of information have not influenced the habits of prevention - cancers are lately diagnosed, as before in the scarcity of information era. This paper analyzes patterns of accesses to the National Cancer Institute website (already described in previous articles) as well as contradictions between the purposes and results of cancer prevention campaigns. We identified a reactive pattern of queries which was indifferent to information on prevention, but interested in treatment technologies and news about celebrity's diseases. These findings contrast with the paradigm of the best data for decision making, based in the heteronomy of "banking education", its means and efficacy. We discussthe symbolic power of campaigns under the theoretical framework of emotional heuristic models - analytical tools rarely employed in studies of risks, but here considered essential elements to the comprehention of public perception of health. Ambiguities are portrayed and as well as its pendulum between certainties and uncertainties in the midst on which they are formed. It is discussed the risk tripartition - as perception, analysis and policy, the latest posed as a public clash between the first concerning the major risks aligned to their historical circumstances.

> **Key words** Internet, Media and health, Health communication, Health sociology

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#### Introduction

Progress in IT and communication has developed as fast and as frequently as the changing implications that arise from it in the field of sociological observation. With the advent of broadband, we see qualitative advances in the 'unidirectional' (*distributive*) Internet toward the territory of health and 'self-tracking' as a field of plentiful material for the sociology of biopolitics<sup>1,2</sup>. We believe that description of new meanings produced by these techniques in their subjective, social and political repercussions is an extremely important subject.

In spite of the economic development of recent decades, social and economic inequalities in Brazil are also reflected, now in new formats, in the scope of access to information and communication technology3. In relation to the quantity of accesses to information on health, the base of the Brazilian socio-economic pyramid has become increasingly narrow. Based on consultations of Google trends (open access) one sees the exponential growth of visits from the poorest regions of the country. However, despite this wide access, little is known in the qualitative dimension about the social appropriation and practices. Thus, the our core question is about the correspondence between the volume and the nature of information sought, and its use – concerning the subscription to new habits for protection of health. In parallel to the expansion of the Internet, one sees that cancers capable of early identification continue to be diagnosed late, at an advanced stage<sup>4</sup>, in the Brazilian Unified Health System (SUS) to exactly the same degree as in the time when access to information was scarce<sup>5-9</sup>. There is plentiful documentation in the literature about decisions postponed at the moment of seeking professional support in this field, whether this support is produced in countries of underprivileged socio-economic position<sup>10-12</sup>, or in fully industrialized countries<sup>13-15</sup>.

Summing up, what we seek to portray can be summed up in the perspective of two panoramas. The first relates to the potential offered for points of observation that are perhaps underestimated by observers of the distributive WEB. Those interested in ITCsas an intermediary for observation of social phenomena will certainly be interested by what is written below. The second point, derived from the first, refers to patterns of access to the website of the Brazilian National Cancer Institute (*Instituto Nacional de Câncer* – INCA), which point out the distance between the purposes of institutional campaigns for prevention of cancer and their results in terms of social appropriation of information.

# Search patterns and consumption of information in emerging countries

There are few studies about patterns of access to information in countries that are less socio-economically favored but where there is intense appropriation of the new ITCs<sup>16</sup>. However, the few investigations show significant findings - although they still lack a homogenous methodology, due to the recent arrival of the technologies. With so many other social phenomena, these patterns have broadened and they diversify according to historical, political and cultural imperatives that are peculiar to each terrain of observation<sup>16</sup>. From the point of view of sociology of risk, it is reasonable to admit that such needs may express dangers to which individuals feel more vulnerable and which give rise to the derived decisions<sup>17,18</sup>. In this context, the planners of campaigns that seek to meet growing demand for explanations in the field of primary care could make use of the patterns of access to the web as an illustrative source of references. Surveys in this field have intensified19-22, producing new concepts on the origin and the meaning attributed to collective perceptions, which is considered to be an essential factor for improvement of care structures. In theory, the Internet would represent a valuable resource for self-care if it is to be admitted that the idealized subjects to which the messages are directed are universally proactive. In theory, to provide information would be to promote empowerment of patients, carers and users in relation to their chronic sufferings<sup>23</sup>. Keeping such proactivity in mind, strategies for delivery of messages through the communications media have been considered by the mainstream in this field as the most efficient routes for dissemination of information for prevention of risks. However, here it is appropriate to raise some questions - for example: Could priorities and urgencies for information be influenced by (collectively perceived) difficulties related to access to the health systems' capacity to provide solutions? Could the persistent dissemination of technological advances in diagnosis and treatment create demands that could confuse the interpretation of institutional messages for protection of health? Could all these elements, having varied effects on multifaceted contexts, generate patterns of searches that would be a useful subject for study by the formulators of public healthcare policies?

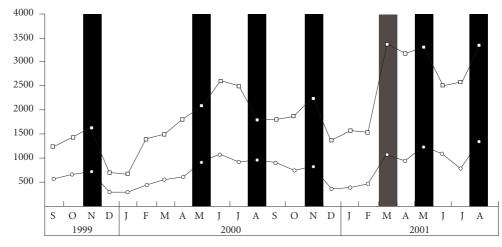
Some recent published works reaffirm aspects that are central to what is being asked here. There are descriptions of differences between patterns of use that refer to socio-economic status, gender, social capital and ethnic group<sup>24</sup>. A relative disinterest for information on prevention (as we have observed in prior studies) is described in the less favored socio-economic segments of society (but not among them alone, depending on the subject). Visits to websites of specialized centers in a search for content related to medical technology are more frequent16 and the patterns of access and consumption of information are coherent with self-reported health<sup>25</sup>. Summing up, the amplified perception of vulnerability is linked to searches that acquire the format of self-diagnostics, in the perspective of innumerable potential risks whose presence is felt and expected. There are increasing numbers of *reactive* searches (particular to the most vulnerable), in contrast to proactive searches –particular to subjects who are conceived of as being rational consumers of data on prevention of diseases<sup>23</sup>. In other words, selfcare consists of pre-emptive use of information<sup>26</sup>, in service of the immediate and urgent from the point of view of a vulnerable condition.

# Patterns of reactive queries and log files of institutional websites

Based on observation of log files (of visits to the site), it is possible to estimate patterns of searches (queries) and of interest with a level of detail sufficient to characterize the subjects that are most relevant to the moment<sup>27</sup>. This is already routinely employed in e-Business - navigation tracking technologies have moved the center of business from the production chain to the process of consumption of information about products. The scrutiny of browsing indicators in this field has, classically, been the subject of study of knowledge related to marketing and sales. In the present case, in contrast to estimates based on generic search engines (such as Google or Bing!), the study of queries centered on institutional websites - accepted sources of secondary communication – provides access to the institutional discourse in pure form, without the commercial bias or the technical disputes that are peculiar to primary communication (between peers)28 and to informal communication between members of the non-technical public. Using software (log analyzers that analyze records of accesses, identifying patterns of interest based on aggregate figures for individual visits) it is possible to estimate the focus/level of interest of queries in specific subjects, indicating, as in e-Business, the direction of perception among options. In previous works we have estimated the average monthly numbers of sessions (visitor sessions), return ratios (number

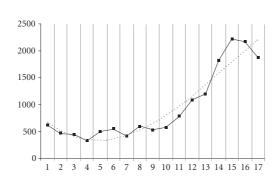
of accesses / number of users in the month), pages and files most accessed, and the average time of permanence in each page, seeking points of observation that serve as drafts of outlines of the symbolic market in this field. Although there is no way to effectively quantify the social interest that will unveil the meaning of the practices, we believe that there are interesting vestiges that confer consistency on the patterns of queries as collective references that should not be ignored. They would represent marks of inscription in the circles of social attention produced by the symbolic capital accumulated in the dynamic of collective exchanges — a theory the in-depth discussion of which is outside the scope of this space.

As an example, we describe on the site of INCA<sup>27</sup> traces of circles of attention linked to fictional items, and to events widely publicized in the media, such as: accesses to pages on prostate cancer, after the death of the Governor of São Paulo State (Figure 1). The diagnosis of leukemia for a character in a TV series (Laços de família, of 2001) also significantly increased the number of accesses to the pages about the disease, and also the average time of staying on the site -enough to characterize a pattern of interest (Figure 2)<sup>27</sup>. Other studies describe similar reactions to works of fiction that give an idea of the scale of their considerable impact, as well as the effect of celebrities of TV, cinema, radio and other media -whether these are shown in industrialized countries or countries of the third world<sup>27,29-31</sup>. Our observations also explore peculiarities about collective interest in pages on types of cancer during institutional campaigns32; patterns of access were estimated over three years with a focus on the dates dedicated to campaigns for prevention of cancer -World No Tobacco day (May 31), National Anti-smoking Day (August 29) and National Combat Cancer Day (November 27). The paradox of the accesses that diverged from the founding intentions of the campaigns, linked to promotion of health and prevention of illnesses, was described. National events set off more intensive searches for content on illnesses already suffered and the new treatment technologies. By contrast, the interest in pages on prevention or early identification of cancer continued to be insignificant. More recently, we have identified a similar pattern of accesses linked to self-examination of the skin and to protection against overexposure to UV radiation during the summer months<sup>33</sup>, and also during campaigns for prevention of skin cancer, over four years (Figure 3). The conclusions derived from these observations lead us to questions: In the cultural dimen-



- -□- What causes cancer?
- —> How to prevent cancer?
- Months of campaigns and national holidays
- Death (with campaigns and national holidays: interior of São Paulo)

**Figure 1.** Monthly means of visits to the pages on causes and prevention of cancer on the site of INCA; and effect of the death of the Governor of São Paulo State



Leukemia pages
Trend line (polinomial)

Monthly mean before TV series: 805,91 (SD=383,35).

Monthly mean during character's disease: 1597,2 (SD = 269,9). (increase of 98,18%).

**Figure 2.** Monthly means of visits to the page on leukemia during the time when a character on a TV series ('novela') was suffering from the disease.

sion, do cancer prevention campaigns promote health, or illnesses, or technologies? Does curing appear to be more interesting than prevention?

#### Proactivity versus reactivity

Both in Brazil and in other countries, funds are invested in the production of educative events on health, frequently using formal and technical knowledge that is little accessible to the base of the socio-educational pyramid (this trend is not observed in e-Business campaigns). Beliefs in the power to 'pass the information', based on the 'heteronomy of banking education'34 have been the subject of criticism about this approach's means, costs and capacity to provide solutions. Institutional campaigns planned in this way would not achieve sufficient symbolic power to change the most ingrained values. The polysemy of images and messages, and their appropriations of meanings resulting from them, try to summarize 'the Brazilian' as an average and homogenous category - as in the Health Ministry's 'Guide to Food Education'35. The principal classics of education in health, perhaps influenced by the laws of social marketing<sup>36,37</sup>, take a bet on these strategies' capacity to provide solutions, because they believe the information published will have a direct and linear effect<sup>38</sup>. There are no ways of objectively estimating the impacts generated by these tactics, but the strategies appear not to take into account the peculiarities involved in the multi-culturality of complex societies, and this can result in frus-

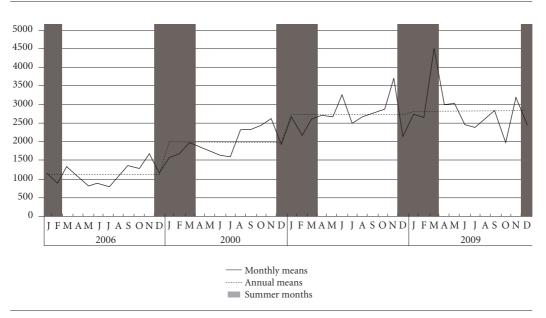


Figure 3. Monthly means of visits to the pages on prevention and self detection of skin cancer along 2006-2009.

trating or paradoxical results<sup>39</sup>. Investing in the direct transmission of knowledge to individuals, they tend to leave out of account the cultural and socio-economic milieus in which these people exist and from which they extract their systems of meaning of truths. Institutional campaigns for protection of health and prevention of illnesses, whether or not they are considered to be activities of 'promotion of health'<sup>40</sup>, still lack careful systems of evaluation that might abandon the phenomenology of impressions over impacts.

Campaigns for prevention of cancer, after decades of experiences with various formats of intervention, appear to exercise a dubious degree of influence in the social imagination. In Brazil, they appear not to take into account the peculiarities of the cultural multi-vectoriality that populates countries whose scale is continental. The influence of events which are otherwise seen as irrelevant - although they have intense regional impact – often results in collective indifference to publicity that is made at an inappropriate time or in an inappropriate way<sup>27,32</sup>. The voluminous flow of information made possible by the Internet and other means of communication sometimes seems to distract the public interest to a place far from prosaic day-to-day measures by directing circles of attention to technologies that hold promise for cure of diseases41. There are projects immersed in the typical logic of consumerism: "better information for better decision"36; or: "without scientifically valid information, the society of proactive consumers would acquire any product"23. In contrast, reviews of the subject state that the consumers with higher levels of schooling, and greater potential for discrimination when faced with a tempting possibility, are the principal victims of fraudulent trading42,43 and rumors on risks to health<sup>44</sup>. In another example, the causality between exposure to UV rays and skin cancer has been popularized now for more than two decades - but even so, 38% of American bathers, although conscious of the risk of skin cancer, have avoided anti-UV protection45. The Australians succeeded in reducing the incidence of new cases of basal cell carcinoma and melanoma only among individuals over the age of sixty46, while among younger people - more assiduous Internet users control of the disease continues to be a challenge (and a priority)<sup>47</sup>.

In the field of social psychology, it is questioned<sup>48,49</sup> whether there is a direct link between knowledge of practices and actual changes of behavior. This understanding was essential, although incomplete, in explaining failures of campaigns to orient behavior, aimed at subjects conceived as having a proactive profile and oriented toward rational decisions<sup>47</sup>. In the field in question, cognitive dissonance has led to questioning of the effectiveness of models of campaigns based on pure information – which were effective among older Australians, but not oth-

ers<sup>47</sup>. Certainly there are socio-cultural peculiarities to consider, perhaps linked to subjects that remain in existence in persistent local cycles of interest<sup>36,39,50</sup>. Perhaps individuals' insufficient individual knowledge about their own state of health, associated with the 'culture of medication' and added to the highlight attention given to technological advances in the field of therapies, exercised 'anti-prevention influences' on the culture. At the same time, there are authors who identify, in certain social segments, an amplified perception of overexposure to risks, joined with the enunciation by the media of dangers arising from little-defined factors, of hardly proven scientific validity or only precariously understood by the public. According to these authors, the reaction of US bathers is attributed to the 'ostrich effect' linked to the idea that we are submerged in a sea of carcinogens against which there is no protection<sup>41,51,52</sup>. Perhaps the cancer risk linked to certain factors still lacks sufficient structuring power to change ingrained habits: depending on the point of observation and the explanatory models, many questions continue to exist in a terrain that is subject to numerous versions in mutual contradiction.

# Risks, affect and reactivity

We return to the central questions: Do cancer prevention campaigns promote health, or illnesses - or technologies? Is self-diagnosis, in a context of perception of vulnerabilities and inefficacy of healthcare structures, perceived as being more accessible than the information for prevention? Could it be that reactive searches are governed more by fear than by reason? Does the risk of cancer carry more weight than its prevention? In the society of risk, do the fluidity of uncertainties and imminences<sup>53</sup>, and the discredit of protection technologies, take the upper hand? These questions can be illustrated by more recent texts and analytical tools not classically employed in sociological studies on risks - heuristic models of the emotions that lead to decisions, and to the interests in and searches for information that precede them<sup>54</sup>-<sup>57</sup>. In this point of view, emotions (or *affects*: as discussed below) guide our choices through reactive impulses and mental shortcuts which set out options. In this context, it would be reasonable to admit that the behaviors and reactive queries perhaps arise within the groups of associations linked to sensations perceived as 'danger', 'fear', 'risk', or 'insecurity'54,56,58. Going less far than this would be affects or inclinations that are not objectifiable (and not yet discursive), from which emotions

and perceptions or risk originate. The emotions would align in each chain of reactions as efficient vehicles and routes for flight in the imminence of disasters and boosted by affects that come before them. The whole of the process would be succeeded by legitimating rationalizations, which judge affects/emotions as 'intuitions' that are parallel to and independent of the process of rationalization. Such points of view are grounded on distinction between corporified sensations, through which the emotions, allegedly, comprise an intuitive 'experimental system'. The latter, as an 'analytical system', would, then, employ the logical, normative, factual and mathematical, but while also informed by its emotional, more agile, counterpart. Lacunas and icons are thus created that give more solidity to the sketches of danger, sometimes taking the form of industrialized products, and sometimes illnesses that bring with them stigmas of suffering and physical degradation. These icons stigmatize themselves in the collective imagination, in expectation of external stimuli -such as celebrities or characters in television fiction becoming ill. The perception of a critical level of risk - directly related to the self-perception of vulnerabilities bequeathed by failings in assistential or educational support – does not find in prevention campaigns the gestures of hope that it needs. On the contrary, this bring us back to circles of interest. As Gregory et al.<sup>59</sup> have observed, certain stigmas are created, mixed with each other and give origin to others at every moment. They are reproduced as structuring elements in the public perception of health, influencing the acceptance or rejection of scientific and technological innovations. Thus the tripartite nature of risk as 'perception' (subjective), 'analysis' (objective) and 'policy' is created, this last element being represented by the public standoff between the first two in the contingency of historic moments<sup>17,60,61</sup>. These standoffs, typically, involve actors portrayed by the analysis of the literature of risk as 'excessively emotional lay people' in opposition to the specialized or 'analytic' evaluators of risk<sup>57</sup>.

On the subject of this political standoff of risks, it becomes important to define concepts that frequently mix with each other, leading to contradictions and even to sensualist or fallacious models. 'Emotions' and 'affects' frequently appear to conjugate together, or to contradict each other in the texts that deal with *heuristic commotions*<sup>59</sup> that orient collective perceptions and decisions. According to the authors who are guided by concepts of the philosophy of Spinoza and Deleuze<sup>62</sup> those emotions would be better defined as *affects* or 'non-conscious inclinations'

- consequently pre-linguistic and not discursive - still external to the domains of the emotions that can be verbalized. The affectus of Spinoza is linked to the capacity, in the course of an experiential state, to affect and to be affected by another, implying modifications in the disposition to action<sup>63</sup>. In opposition to affects, although taken in a relationship in which one presupposes the other, ideas are purely rational and representative modes of thinking linked to what can be called the 'objective reality'. Differently, affects do not have a representative character - they are inclinations to do with the will in search of objects of representation. In Spinoza, idea and affect are two modes of thinking that are different in nature, irreducible in the relation of one to the other, and in a certain way add an interesting complexity to the theory of heuristic commotions. Certainly the ambiguities of the risk culture involve a swing between certainties and uncertainties, with forward and backward steps which take place in dynamic and plural contexts in the midst of which risks are reshaped.

The anthropologist Deborah Lupton criticizes the approximation of these polar notions to psychometric cognitive models of evaluation of risks and taking of decisions that are reduced to groups of relationships between cause and effect, under variables that make possible linear estimates of consequences<sup>57,61</sup>. From the philosophical point of view, a certain essentialism can be perceived in the construction of those models that makes us believe in elementary dualities, which accept the irreducibility of a universal silent nucleus. At the extremes of these concepts, the attention to the simplifying philosophical perspectives is essential. Without grey areas, these only have weight based on linearity that is insensitive to ambivalences and social complexities. From the point of view of sociological texts, such notions of 'intuitive operations' would be expanded far beyond the behavioral psychological models, as constructions derived from understandings about collective, perhaps even contradictory, experiences and perceptions<sup>64-66</sup>. Although taking different and frequently contradictory internal and external resources as a starting point, they place themselves as a productive way of incorporating discursive and experiential dimensions of emotion/affect<sup>66</sup>.

Both under dual perspectives and under other more expanded points of view, affects (in contrast to the risks in a dimension of para-factuality constructed by probabilities) are immaterial in the individual dimension, although under the discursivities of the political dimension they are expanded as imminent, never insubstantial, exigencies. However, when discursively manifested (as in prevention campaigns) they leak out into the rational dimension, although substantiated as collective experiences and memories<sup>67</sup>. It does not appear to be, solely, the multiplication of individual constructions, but, beyond this, a *shared discourse* that brings together biographies and appeals to our reason from the inside out, and vice versa.

#### **Syntheses**

With the advent of new ITCs we will have access to substantial knowledge about threats, although the certainties about how to deal with these threats appear to be plural and desubstantialized, although frequently iminent and demanding. With the popularization of ITCs some strategies for physic survival have become accessible since entry to the world of information has expanded. However, to a certain degree (and in particular in relation to the mass media) this world has established itself in a dubious function of both problem and solution. Following a loud enunciation of risks, there follows the incompleteness of the protective measures, thus creating a feedback cycle. The access to increasingly qualified information sounds like a reasonable psychic reaction strategy for reconquest of the lost control.

On the process of self-reflexive individualization of conducts and life stories, Ulrich Beck observes that biographies have been transformed into courses to be produced by each individual<sup>53</sup>. In other words, we demand decisions in relation to health, prevention habits and the option to seek professional help or the support of Dr. Google (among so many other day-to-day options). In the same way the (perhaps irreversible) consequences arising from such options should be assumed both as "a focus of action and an agency of planning"53 in relation to the affiliations to the available truths selected by affects. The risks have become omnipresent, taking the form of all the sinuosities of the management of daily life, although perhaps de-substantiated from their causal threats.

In fact, the technological resources of substantiation available in mutual influence with the cycles of interest that nourish and are nourished by the communications media (by desubstantiating products of the former) produced effects that transcend the relationships between doctors and patients, and also those of subjects with their own bodies. The risks to health become pearls of the politics, education and various other dimensions of the social world<sup>68</sup>. Citizens clamor for environmental sustainability of energy sup-

ply, information about the composition of foods, they consume literature about self-help and frequent *Pubmed.com* in search of updating on technologies of cure and diagnostic tests. In this context, the risks to health are contingent constructions, of a normative character, linked to definitions of the human, the type of society that is being sought and the ways of achieving it<sup>69</sup>.

#### Final considerations

We believe that the characteristics of reactivity of the queries to the site of the Brazilian Cancer Institute are perhaps sketching cultural vectors on which influences of various types apply. Certainly the reduction of inequalities would be supported, above all, in this scenario, firstly in the capacity for search, full and amplified comprehension, critical contextualization and, finally, choice of the most expensive and trustworthy information when taking care of one's self. In Brazil digital empowerment took place through the portal of the market for goods and consumption and not by the access to full citizenship, education, health and, above all, the critical capacity to identify lapses and the political opportunity to make progress in these fields. It is important to consider that, in Brazil, the simple quantitative expansion of accesses without reduction of social-educational inequalities compromises critical aptitude in relation to the information accessed. The low level of schooling, the limited capacity for reading, insufficient concentration and functional illiteracy are obstacles to comprehension and critical absorption of the information, and from this situation, affects emerge for prevention of risks. Perhaps the perception of such insufficiencies and their consequent vulnerabilities is expressed in the desire for contents of precarious and urgent 'self-diagnosis', as an effort to immediately overcome the fears linked to adverse conditions of life. It is, thus, reasonable to suppose that the symbolic strength of utility and relevance of contents that supply conditions for self-scrutiny might now supplant (in the collective imagination of the more vulnerable segments of the population) contents linked to change of habits and customs as a way of avoiding risks.

Thus, search trends become centered on urgent pre-emptive action in the context of a perceived adverse present. It is reasonable to believe that the segments of the population with low level of schooling – now with increasingly facilitated access to the web, but still not served by primary healthcare policies – would be those that are

most susceptible to being influenced, and most 'reactive' in their searches/queries. Perhaps this may become even clearer in the medium term, as access to the Internet is further popularized, with connections increasingly facilitated through LAN Houses or by popularization of mobile access through open wireless networks. In a sense, reactive queries perhaps also indicate failures in the organization of our health system - centered on services of high complexity and primary care systems that are still not supported in their function of public explanation (and perhaps for this reason, still not very effective in terms of providing solutions). The growth of the quantitative dimension of access to information via Internet can, thus, be seen from an either negative or positive point of view. In the latter aspect, it is positive to consider the growing number of individuals seeking, as a way of exercising their citizenship, the best information about the health services. At the same time, one clearly perceives a negative dimension in those who no longer trust the state and its capacity to meet their demands.

The rationality expressed in the patterns of access produced by the instances of 'affectus' would also serve as input for their mercantilization, and for the idea of portraying the SUS as precarious – both approaches being highly perceptible in news reports. So: more information did not, necessarily, mean more prevention, because the failures in the system continue to strengthen some cultural patterns of distancing from self-care. In this field, efforts for prevention or early detection of cancer are the subjects of institutional communicative processes to which it is fair to reciprocate with inputs for future initiatives.

#### Collaborations

PR Vasconcellos-Silva has worked in the design, analysis and writing; LD Castiel and FR Ferreira had collaborated in the analysis and writing.

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p. 862

## Where it reads:

Paulo Roberto Vasconcellos Silva

It should read:

Paulo Roberto Vasconcellos-Silva

p. 864, 866, 868, 870

# Where it reads:

Silva PRV et al.

## It should read:

Vasconcellos-Silva PR et al.