Consumer-Centric Perspectives on Chronic Patients' Decision-Making: Navigating Emotional Trauma, Sharing Experiences, and Shaping Healthcare Journeys

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Abstract:

This research explores the consumer behavior dynamics inherent in chronic patients' decision-making regarding sharing or hiding their chronic disease. Focusing on cancer patients, we investigate two approaches—solution-oriented and problem-oriented—and examine the emotional and behavioral consequences. For those who share, the study reveals outcomes such as relief, increased resilience, and improved relationships. Those opting for hiding experience emotional suppression, distress, and social isolation. The findings contribute to social sharing theory, emphasizing the importance of considering both the listener's response and the sharer's perception. From a healthcare consumerism standpoint, understanding these motivations provides insights into treatment adherence, health outcomes, and patients' active role in shaping their healthcare experiences. Health professionals can hold these insights to enhance mental health strategies for chronic patients, emphasizing education and support.

Keywords: *Chronic Patients, Sharing Approach, Healthcare Consumerism*
Track*: Consumer Behaviour*

1. Introduction:

Social sharing within the context of chronic diseases, particularly cancer, has been acknowledged as a significant factor in enhancing patients' quality of life (Lai et al., 2017) and contributing to their overall well-being (McLean et al., 2007). Notably, the act of sharing one's diagnosis has been linked to psychological benefits, such as increased acceptance and emotional adjustment (Zhang et al., 2007; Sacco and Yanover, 2006). However, the decision to disclose such sensitive information is often hindered by patients' fears and concerns (Yoo et al., 2010).

Analyzing patients' decisions to share or hide emotions post-trauma from a consumer behavior lens is important and provide practical implications for healthcare service. It sheds light on complex issues affecting treatment adherence, overall health outcomes, and the interplay between cognitive and emotional mechanisms. The roles of social interaction, self-presentation concerns, and the establishment of support systems emerge as important factors influencing patients' choices.

In today's everchanging healthcare landscape, treating patients as informed consumers is of great importance. This approach recognizes patients' active role in shaping their healthcare experiences. Digging into the multifaceted reasons behind patients' decisions in this journey enriches our comprehension of how they actively work and navigate their healthcare experiences. This holistic consumer-centric approach not only contributes to theoretical frameworks but also provides practical guidance for healthcare services to adapt and cater to the unique needs and preferences of their consumers.

The theoretical framework employed here is the social sharing theory, emphasizing the need for communication in response to emotional events. While the two-mode model by Rimé (2009) highlights the significance of verbalizing emotions, it fails in addressing the various approaches individuals might adopt in the decision-making process of social sharing. Therefore, this research seeks to fill both theoretical and empirical gaps by investigating the social sharing process among patients with chronic diseases, specifically focusing on factors influencing the decision to share or hide, and the potential consequences on patients' lives.

Among the existing categories of chronic disease, cancer (Wilper et al., 2008) has been chosen in this qualitative study. Based on the World Cancer Research Fund International report in 2020 cancer touches more than 18 million people around the world. Hence, from a consumer behavior standpoint, exploring the social sharing dynamics within the context of cancer provides valuable insights into the ways individuals navigate these emotional landscapes.

2. Methodology and Results

To gather data, an empirical approach is adopted, with France selected as the study location due to its significant cancer rates (World Population Review, 2021). A qualitative methodology using open-ended interviews is employed, following the relatively unexplored nature of this topic (Miles and Huberman, 1994). Respondents are selected from a nonprofit healthcare center (Institut Rafaël) to ensure a diverse sample, covering various profiles related to chronic cancer patients (N=25, Table 1). This diversity is crucial from a consumer behavior perspective, allowing for a comprehensive exploration of different angles.

To enhance the rigor of the study and ensure the sufficiency and necessity of the collected data, a snowballing technique is applied for sample completion. Additionally, data triangulation is applied to validate the findings and provide a solid representation of the reality experienced by chronic cancer patients (Miles and Huberman, 1994). This consumer behavior-focused approach contributes not only to the theoretical understanding of social sharing but also offers practical insights for healthcare professionals dealing with chronic patients' emotional well-being.

Table 1 Overview of the respondents

No	*Gender*	*Age*	*Type of cancer*	*Marital status*	*Nb. of children*
1	M	64	Prostate	Divorced	3
2	F	48	Skin	Single	1
3	F	52	Thyroid	Married	3
4	F	76	Breast	Married	4
5	F	63	Breast	Divorced	1
6	M	53	Prostate	Divorced	3
7	F	74	Breast	Married	2
8	F	59	Breast	Married	1
9	F	70	Thyroid	Married	0
10	F	63	Endometrial	Married	3
11	F	71	Skin	Married	4
12	F	62	Breast	Married	2
13	M	58	Skin	Single	1
14	F	61	Thyroid	Married	2
15	F	56	Endometrial	Divorced	3
16	F	38	Breast	Married	1
17	F	34	Breast	Single	0
18	F	72	Ovarian	Married	1
19	F	68	Colorectal	Single	2
20	F	39	Endometrial	Single	0
21	F	49	Breast	Married	3
22	F	57	Ovarian	Married	2
23	M	40	Prostate	Married	1
24	F	61	Breast	Single	2
25	M	75	Lung	Single	4

A random number was assigned to each interviewee from 1 to 25 to present some of the quotes.

To analysis the resulted qualitative data and given the lack of developed state of knowledge in the studied area we applied grounded theory approach (Strauss and Corbin, 1990). This systematic inductive method involves making deep and specific efforts to understand the interviewees' ideas to develop new concepts rather than just grouping data under existing theoretical categories (Gioia et al., 2013). In this method, the analysis is structured into three-level analysis, so first phenomena are identified and coded then they are explained through issues, and finally the extracted issues are translated into aggregate dimensions. The resulting model (Figure 1) allows us to create links between the data and theoretical concepts (Miles et al., 2018).

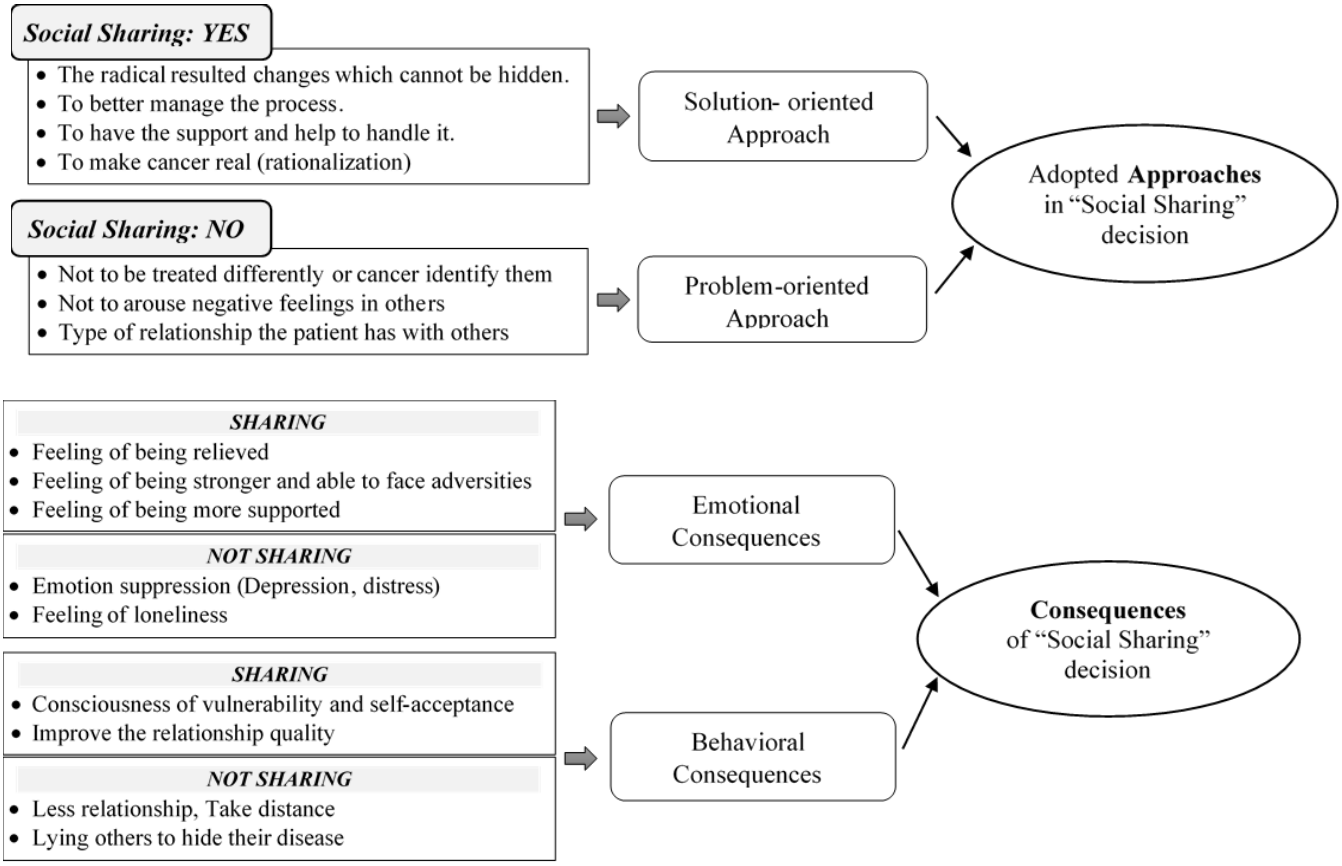
The findings of our study shed light on the distinct approaches chronic disease patients may adopt post-experience, providing valuable insights into decision-making processes and the emotional and behavioral consequences associated with sharing or hiding emotions. According to our results, patients may adopt a **solution-oriented approach**, choosing to share their experiences consciously due to an awareness of radical changes that cannot be hidden (e.g., P (Patient) 2: "They would see it with their eyes! ") . Reasons for sharing include the side effects of treatment, emotional imbalances, and matters related to sexual life. Patients articulate that sharing is perceived as the right way to better manage the treatment process (e.g., P23: " If I hide, I would not be able to manage the treatment process") and receive the necessary support to handle the illness (e.g., P3: "If they know not only, they can support me"). Importantly, sharing emotions is viewed as a way to make cancer more real, contributing to rationalization (e.g., P24: "I always have this experience that talking about my feelings make them more clear for me").

Conversely, the findings highlight a **problem-oriented approach** where some patients decide not to share their cancer experiences. This decision is often rooted in the desire not to be treated differently or have cancer define their identity (e.g., P5: "I wanted them to talk to me the way they always have". The decision not to share is also driven by the intention not to impose negative feelings on others (e.g., P13:"I did not want them to be sad or worry"). Additionally, the type of relationship a patient has with others plays a role in the decision not to share emotions (e.g., P13:"By the way, I do not have anyone who can accompany me during the appointments or who can help me manage my health").

The **emotional consequences** of sharing include a sense of relief, increased strength to face adversities, and feeling more supported (e.g., P19:"Surprisingly after sharing it with my children, I feel relieved"), (e.g., P18: "They help me to be stronger and to fight this battle", and P14: "I am blessed to have them in my life, they are supportive, not in an artificial way but they are real in their supports!"). In contrast, the emotional consequences of not sharing include emotion suppression, such as depression and distress, along with a profound feeling of loneliness (e.g., P22: "I am always stressed that they do not understand about my disease! I am not sure sharing has an effect", and P1: "I feel I am alone in a big black box. I do not want my family to be hurt, and I have to protect them, but I feel I am exhausted").

Behavioral consequences further differentiate the two approaches. Sharing contributes to consciousness and self-acceptance of vulnerability, as one participant shared, (e.g., P6 "After disclosing it to my family, I felt different. Like listening to me talking about it makes it real, and I finally accept it"). Additionally, sharing improves the quality of relationships, with one participant expressing, (e.g., P20: "I could not believe our relationship became strong"). On the other hand, not sharing may lead to having less relationship with the social network and taking some distances, as one participant mentioned, (e.g., P 9: "After the diagnosis, since they were not aware of my cancer, I chose to have less relation with them"). Furthermore, not sharing may involve lying to others to hide the disease, with one participant stating, (e.g., P 25: "I have to chain the lies after that, but it is to protect them").

Figure 1 Data structure



3. Conclusion

In the realm of consumer behavior within the healthcare landscape, our results clarify different approaches adopted by chronic patients, emphasizing the important role of social sharing in navigating the complex journey of living with a chronic illness. Patients opting for the solution-oriented approach, choosing to share their experiences, do so consciously, recognizing that chronic illnesses necessitate permanent changes in both physical and lifestyle aspects. This aligns with existing research indicating that communication among couples facing cancer aids in patients' adjustment to their experience (Hagedoorn et al., 2011). Furthermore, our findings suggest that sharing experiences contributes to the integration of the chronic disease experience into one's self-concept (Mathieson and Stam, 1995), fostering the development of new identities (Zebrack, 2000). This transformative process potentially influences well-being (Brennan, 2001) aids in adjusting to the challenges posed by the illness (Bellizzi and Blank, 2007). Notably, the decision to keep the illness a secret extends beyond avoiding differential treatment; it also seeks to prevent the arousal of negative feelings in others, echoing previous findings that sharing, if done in ruminative ways, may intensify distress (Pasupathi et al., 2016).

Our results contribute to the literature on social sharing by spotlighting that sharing experiences serves as a source of positive consequences, a phenomenon known as 'capitalization' (Peters et al., 2018). This process proves instrumental in managing the psychological impact of trauma, fostering emotional recovery (Rimé et al., 1998), and providing social support linked to tangible physical and emotional benefits for chronic patients during their journey (Toledo et al., 2020).

Emotionally, sharing results in feelings of relief, increased resilience, and a heightened sense of being supported. These positive emotional consequences align with previous findings demonstrating that sharing negative experiences can lead to growth-related meaning-making and greater well-being (McLean et al., 2007). Behaviorally, the decision to share correlates with heightened consciousness of vulnerability, self-acceptance, and improved relationship quality, echoing the concept of 'Affect labelling' (Stanton and Low, 2012), where sharing facilitates cognitive processing of emotions.

Conversely, the decision not to share reveals potential negative consequences, encompassing emotional suppression, distress, feelings of loneliness, distancing from social support networks, and the fabrication of lies. Suppression of emotions following trauma and avoiding sharing may result in both intrapersonal and interpersonal costs (Cameron and

Overall, 2018), highlighting that not sharing negative emotions post-trauma could potentially lead to additional trauma for chronic patients.

In conclusion, our study challenges previous empirical findings on social sharing by not only bringing awareness to patients regarding their emotions but also emphasizing the positive emotional and behavioral consequences of 'expression discharge.' The study underscores the impact of a perceived supportive social context in the decision to share post-trauma experiences. It also contributes to sharing theory, emphasizing the critical role of considering both the listener's response and the sharer's perception of the listener's reaction in the decision to share (Rimé, 2009).

In the global context of increasing chronic diseases, particularly cancer, the potential negative consequences of such illnesses on societies are gaining significance. Policymaking organizations and health professionals should prioritize mental health and well-being strategies for chronic patients. Educating patients on the solution-oriented approach to sharing and encouraging social skills development and strengthening social ties align with effective strategies. Caregivers play a key role, and their attitudes impact the emotional benefits of sharing (Figueiredo et al., 2004; Manne et al., 2004), emphasizing the need for increased social awareness and cultural knowledge in this domain (Wortman and Dunkel-Schetter, 1979).

Our research has some limitations that can provide interesting avenues for future studies. This study investigates social sharing among cancer patients, and we encourage researchers to focus on understanding this phenomenon and its consequences among caregivers as an important source of emotional support. Another interesting avenue for future research is to study whether social sharing contributes to the medical consequences, such as reducing the physical consequences of the illness or improving the process of chronic patients. While our research provides valuable insights, it has limitations that offer avenues for future studies. Exploring social sharing among caregivers as a crucial source of emotional support and investigating its potential contributions to medical consequences could be fruitful areas of inquiry. Additionally, replication of our study with a randomly selected and more heterogeneous sample would enhance the generalizability of the results. Overall, our findings contribute to the understanding of social sharing dynamics among chronic patients and provide a foundation for future research in this critical area.

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