Transitional Self-Disappear: The Journey of Cancer Survivors to Self Re-Coherence

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Abstract

Purpose

People who experience cancer often face serious and unpleasant challenges in understanding their past, present, and future. They think they have lost their lifetime, agency, and interpersonal relationships, and no longer know their bodies. These experiences can change survivors' perceptions of themselves. Therefore, the present study aimed to develop a deep theoretical understanding of the change of self in cancer survivors.

Methods

Semi-structured interviews were used to collect data. Interviews were conducted with 17 cancer survivors, 2 oncologists, and 2 family members of survivors. In this study, grounded theory methodology was used to explore the process of understanding and experiencing "self" in cancer survivors.

Results

The present study generated a model about the change of self, with the main concept called "transitional self-disappear", which is understandable based on the concepts of self-disruption (temporal disruption, highlighted body, interference in the agency, - individual-self disruption, over differentiation, relational self-disruption, and painful emotional experiences), self-reconstruction strategy and quality of self-coherence; and occurs in the cancer-based contextual experiences and individual-environmental preparedness.

Conclusion

This model illuminated the complex paths and roads of the survivors' journey from self-disappear to self reconstruction/re-coherence. A healthier experience of this journey can be facilitated by the transcendence of the "self" conceptualized in the past, and the promotion of specific (cancer-based contextual experiences) and general (individual-environmental preparedness) conditions.

Introduction

The healthy of the "self" requires the experience of the continuity of “self” [1–6] which is at the center of finding meaning [4, 7] and is also a vital issue for one’s psychological well-being [5, 6]. But the horrific experience of cancer seems to disrupt the normal flow of life story and its sense of coherence, because in the presence of chronic illnesses, including cancer, a person's daily actions and expectations about his/her life suddenly change [8], the person feels that he/she does not have control in some areas of life [9], the person's relationship with his/her body changes [10, 11], and confront with mortality and death [11]. Also, patients with cancer often have unmet social support requirements and emotional needs [12].

A qualitative study of cancer survivors in Mexico found that they face challenges including cancer stigmas, distress from physical change, loss of control and attitude about planning, family as a supportive source, and

financial problems [13]. In such circumstances, one may be required to future reappraisal [14] and reorganize his/her standards and beliefs and values system [15]; and perhaps it is because of the experience of such challenges that chronic illness leads to the imposition of changes and redefinition of patient roles and responsibilities [16]. Thus, the experience of cancer conditions may impose changes on a person's understanding of him/herself.

Thus, the issue that how is an understanding of self and its transformation process in patients with cancer necessitates conducting in-depth and first-hand qualitative studies. But, in the context of chronic illnesses, concepts related to change of identity/self have often been investigated in the studies of Western and developed countries researchers [10, 12, 13, 17, 18], and they have not been considered in the socio-cultural context of the Middle East countries, especially Iranian society. However, the cultural and socio-economic conditions of a particular society in which a person with cancer lives have some implications and meanings about the experience of life in the presence of cancer illness [16]. Therefore, understanding this process is very important in the cultural and socio-economic context of Iranian society. For this reason, the present study, which has basically used a qualitative method, addressed the question of how is the change of self in cancer survivors in the context of Iranian society?

Methods

In the present qualitative research, the design of systematic grounded theory [19, 20] was used. Also, In the present study, the COREQ standard checklist [21] was used. The research population was cancer survivors referred to cancer treatment centers in Tehran (Iran) selected based on inclusion/exclusion criteria. Inclusion criteria included these cases: age range 20 to 50 years, informed and satisfactory readiness to participate in the research. Exclusion criteria also included: suffering from other chronic physical illnesses, substance use, and a history of imprisonment. Based on theoretical sampling, 21 participants (17 patients, 2 oncologists, and 2 family members) entered the research. The information in Tables 1 and 2 includes the demographic characteristics of the participants, according to their self-reports.

Table 1
Demographic Characteristics of patients with cancer

Code	Age	Sex	Education	Marriage Status	Interview duration	Cancer Type	Time of Diagnosis	Treatment Status
A	36	M	Associate	Married	60 min	Glioblastoma, Right Side of Head/grade 4	2019, April	Chemotherapy, Don't respond to treatment
B	47	F	Associate	Divorce before illness	95 min	Cervical Cancer, Type I	2018, April	End of treatment
C	41	F	Master	Married	67 min	Breast Cancer / Metastasing to Bone, Sternum, and Legs/grade 2	2018, June	End of treatment
D	50	F	Diploma	Divorce before illness	70 min	Left Ovarian Cancer, Metastasing to thirteen points in the Body	2018, September	The patient canceled the last 2 sessions of chemotherapy.
E	33	F	Bachelor	Married	100 min	Cervical Cancer, Type I	2017, September	End of treatment
F	42	F	Associate	Married		Right breast cancer / left breast Metastasis in the 2017 June	2017, June - 2019, May	End of treatment of the previous period / in the middle of the treatment process of the current period of the illness
G	50	F	Associate	Married	43 min	Breast Cancer / Lymph Nodus Metastasis / Progressive Type / grade 3	2019, September	End of treatment
H	49	F	Bachelor	Married	40 min	Breast Cancer, grade 1 / with the possibility of Lymph Nodus Metastasis	2019, February	End of treatment
I	31	F	Bachelor	Married	59 min	Acute Myeloid Leukemia (AML)	2019, August	End of chemotherapy / On the waiting list for Stem cell transplantation

Code	Age	Sex	Education	Marriage Status	Interview duration	Cancer Type	Time of Diagnosis	Treatment Status
J	48	F	Bachelor	Divorce before cancer	42 min	Breast Cancer/grade 3	2019, April	End of treatment
K	29	M	Bachelor	Single	80 min	Hodgkin's lymphoma, / grade 1	2019, May	End of treatment
L	42	F	Diploma	Single	62 min	Breast Cancer/grade 2	2019, August	End of treatment
M	38	M	Bachelor	Marriage after cancer	48 min	Testicular cancer / Liver and Lung Metastasis	2010, July	End of treatment
N	48	F	Master	Death of a spouse before cancer	54 min	Breast Cancer/grade 3	2020, May	He has had a Chemotherapy session so far.
O	37	F	Diploma	Married	57 min	Colon Cancer / grade 3	2017, June	End of treatment/ Doing the course of radiation therapy.
P	49	M	Diploma	Married	44 min	Colon Cancer / grade 4	2016, April	End of treatment
Q	43	F	Bachelor	Married	65 min	Breast Cancer / Recurrence after 9 years/grade 3	2016 April – and Recurrence in 2020 July	End of treatment of the previous period / in the middle of the treatment process of the illness current period

Table 2
Demographic Characteristics of Specialists and Families of patients with cancer

Code	Age	Sex	Interview duration	
R	49	M	40 min	Oncologist
S	44	M	42 min	Oncologist
T	36	F	65 min	Spouse of a person with cancer
U	30	F	52 min	Sister of a person with cancer

The interviewer had no contact with the participants before beginning the study. Interviews were conducted via video call (WhatsApp). Then, each interview was transcribed. None of the participants in the study dropped out. The sampling reached saturation from patient No. 15 (interviewee O), and the codes extracted from interviews 16 and 17 did not have added value for the explanatory capability of the extracted model. Also, 2 oncologists and 2 family members of patients with cancer were interviewed. This action paved the way for the formation of triangulation, by providing evidence from numerous sources [20, 22]. However, from these 4 interviews, no new data was observed that would develop or modify the model evolved from patient interviews. The interview was conducted by the first author (Interviewer profile: Male; Ph.D. student in Health Psychology; Psychotherapist; Passing a training course in qualitative research and grounded theory). Initial coding was done by the first author and then reviewed by other authors. Then, the extracted codes and categories were reviewed by two out-of-study psychology Ph.Ds. The process of collection and analysis of research data has been drawn in Fig. 1.

Results

In the present research, five categorical clusters appeared: Self-Disruption, Cancer-Based Contextual Experiences, Individual-Environmental Preparedness, and Self-reconstruction Strategies, and the Quality of Self-Coherence; and the relationship between these five concepts have been understood by the major concept of "transitional self-disappear". Categories and components of 5 clusters can be seen in Table 3.

Table 3
Clusters, categories and components of the "transitional self-disappear" model

Cluster	Category	Component
Self-Disruption	Temporal disruption	Touch of death, dark future, confusion in present, dissolution of the past.
	Highlighted Body	physical symptoms (severe pains, fatigue, and so on), sexual problems, physical dysfunction, bodily losses, damage to beauty, the spread of illness in the body, the continuation of illness in the body, an external organ (such as a cane) to the body, weight change, and the body in the center of attention.
	Interference in agency	Lack of personal control, dependent on others, lack of interpersonal control, and lack of job agency.
	Individual self-disruption	A feeling of inner change, confused, worthless feeling, cognitive weakness, and doubt about personal interests and goals.
	Over-differentiation	"Why me?" question, becoming unusual, and increased differentiation from others.
	Relational-self disruption	Changing meaningful relationships, abandonment/rejection by others, intra-interpersonal contradictions (contradictory perception of himself and others of his current feelings and abilities), and Family concerns.
	Painful emotional experiences	Fear, despair, hatred, anger, anxiety, shame, guilt, sadness, regret, and loneliness.
Cancer-Based Contextual Experiences	Unexpectedness	-
	Cultural attitudes	Cancer as a catastrophe, and death.
	Explanations of the illness	Action retribution, destiny, consequence of unhealthy behaviors, and psychological stresses.
	Cancer metaphors	Cancer as a opponent/enemy, violent guest, and inspiring.
	Social feedback	Social judgments, weakening supports, annoying curiosities, and hateful compassion.
	Medical experiences	Horrific predictions, drug consequences, and long-term post-treatment consequences.
Individual-Environmental Preparedness	Characters and coping strategies	Traits, coping styles, and values.
	Financial problems	-
	Health system performance	inadequate training, weakness in counseling, specialists' ambiguous speech, misdiagnosis, and drug/treatment deficiencies.

Cluster	Category	Component
Self-reconstruction strategy	Making theme	Family theme, spiritual theme, personal theme: self-idealization (building a resilient and heroic self-image against cancer) and self-centeredness (special emphasis on one's needs, compared to past neglects), and symbolic survival (doing something or creating something that makes a person symbolically stable and alive).
	Agency-seeking	Resuming activities, showing his/herself as a normal, and fighting illness.
	Redefining Identity	Redefining the body, redefining goals, and acceptance of illness identity.
	Denial of illness identity	-
	Considering illness as a stage	-
Quality of Self-Coherence	Adjusted coherence	Awareness, valuing life, patience, and relationship promotion.
	Unadjusted coherence	Isolation, interpersonal sensitivity, irritability/aggression, gloom, and wanting death.

Self-Disruption. The concept of "self-disruption" includes several various components that indicate a kind of cracking and gap in the experience of self and the emotions associated with this experience. By abstracting from the data, the category of self-disruption seems to be a antecedent to the phenomenon of "transitional self-disappear". In the following, each of its 7 categories is described:

1- Temporal disruption refers to the point that by touching and a close encounter with death, patients think they have lost the past, and the phenomenons of cancer and death are dominant on their present time, and the future is ambiguous and dark: "*Those early days when I was newly infected the future was dark for me. I do not want to think about the future now. I thought I would not be alive any longer for another four months (interviewee N)*".

2- Highlighted body refers to the point that due to severe physical experiences the person's body is in the center of his/her attention and monitoring more than before, and it seems that a rift is created between the person and his/her body: "*I think I am a imperfect creature right now. That day I told my husband that I am no longer a woman at all, so I am imperfect (interviewee E)*".

3- Interference in agency reflects the feeling in a patient that she/he has lost agency and control over his/her roles, tasks and actions of life (individual, social and occupational): "*Compared to before my illness, I lost a lot of ability to do tasks. Well, one of my hands does not work much as before. I have to be dependent on others (interviewee J)*".

4- Individual-self disruption indicates that many people with cancer state that they are different from someone they have been in the past in terms of interests, goals, inner values, and so on: "*I am very different from the person I was before; one varies very much. I was completely another person before. I was very good. I am not like the previous person at all (interviewee B)*".

5- Over differentiation means that when people are affected by cancer, are faced with the ontological question, "Why me? Why was I chosen to have this illness and not others?". Also, they feel that their experiences and flow of life have become very different and unusual, and their distinction from others has increased: "*I am very different from people who do not suffer, in terms of my ability, in terms of my beauty (interviewee J)*".

6- Relational self-disruption indicates the disturbance, being threatened, and the fragmentation of a person's definition of themselves in relation to others; because after getting cancer, significant relationships and mutual bonds of an individual are damaged. In addition, the affected person with the idea of his possible absence in the future has important concerns about important relatives and his/her relationships with them: "*Ninety percent of people with cancer, like me, are those who are not seen by those around them, and have put them aside (interviewee B)*".

7- Painful emotional experiences refer to a range of unpleasant emotional experiences that occur after getting cancer and damage to various dimensions of the "self: "*Ever since I got cancer, these feelings have generally been inside me, perhaps a deep nostalgia, perhaps a deep disillusionment, frustrated heart, perhaps a heavy disgust (interviewee L)*".

Cancer-Based Contextual Experiences. This concept means a set of socio-cultural experiences (a set of attitudes, discourses and reactions in society towards cancer) based specifically on the experience of cancer that patients with cancer face it. These experiences can affect the sufferer's self, which is now undergoing a kind of transformation.In the following, each of its 6 categories is described:

1- Unexpectedness is related to this cultural attitude that patients considered themselves far from cancer, becuase everyone believe only certain people get cancer, that is, people who have behaved wrongly and sinfully in their lives. So everyone knows him/herself away from cancer and experiences it unexpectedly: "One always thinks that this illness is for others and never suffers from such a thing (interviewee C)".

2- Cultural attitudes indicate the viewpoints of community members and those around the survivor about cancer, which included two ideas and beliefs: catastrophic (getting cancer is a very big and unsolvable catastrophe) and mortality (getting cancer means the end of life and death). "*People around me said that it seems that a person who refers to the hospital for cancer will really die (interviewee K)*".

3- Explanation of illness describes that cancer is usually considered as a retribution of past errors and sins, being chosen by the destiny (God, fate, world, and so on), the consequence of unhealthy behaviors and psychological stresses: "*In our culture, it is believed that whoever does the wrong and sinful thing will finally get the answer (interviewee O)*".

4- Cancer metaphors explain that cancer was usually known as "opponent/enemy" (rival and enemy who has attacked the person), "violent guest" (uninvited guest who is not an enemy but it is not pleasant either), or "inspiring" (a messenger that wants to inform the person): "*Cancer illness is really an enemy that is hitting from within (interviewee M)*.

5- Social feedback indicates the unpleasant reactions and behaviors of those around towards a "person with cancer": *"A man said, "What this cancer is, it's all the expense, the cost of the pain, it is better that he (A child with cancer) died, believe that his mother lives easier from now on. I hated what he said (interviewee E)".*

6- Medical/ medicinal experiences explain unpleasant conversations and interactions between the patient and the treatment team and others about cancer and form a part of the survivors' lives: "*The doctor told me that you would experience severe symptoms, and you would not survive for more than six months. He said we would start with chemotherapy but only six months (interviewee J)*".

Individual-Environmental Preparedness. This concept includes a set of general individual or social conditions and factors that are not specific to the experience of cancer, but affect the way a person encounters what has happened. In the following, each of its 3 categories is described:

1- Characters and coping strategies explain a person's previous coping styles, traits, values, and can affect in facing cancer in confronting with the main phenomenon: "*I am generally a person who tries to cope with the conditions, that is, I was the same before the cancer illness, I do not take it hard (interviewee C)*".

2- Financial problems explain the very high costs of treatment and the financial problems of people at the time of getting cancer, that can affect how a person copes with the illness and its consequences: " I had to sell my daughter's golds, for chemotherapy *(interviewee K)*".

3- Health system performance refers to the set of inefficient programs, functions, and actions of the health system and its activists (including officials, specialists, nurses, service groups, and so on) that are not limited to cancer illness, but it can affect the confrontation experiences and procedures of people with cancer: *"Unfortunately, doctors and nurses do not provide enough education about the course of cancer symptoms, and there is no proper nutrition counseling (interviewee G)".*

Self-reconstruction strategy. This concept refer to strategies that are intentionally or unintentionally used to reconstruct the "self" that has been disrupted and disappeared in facing cancer. In the following, each of its 5 categories is described:

1- In the making theme strategy, after getting an illness, one tries to find a new theme or redefine some former possessions differently to make the "self" coherent around it: *" I feel that my mission is just to get these two children to a stage in life where they can be independent, and no longer depend on or need anybody, then I have nothing to do in this world (interviewee O)*".

2- In the agency-seeking strategy, a person tries to regain a sense of agency and control over life by resuming activities, showing his/her "self" normal, and fighting his/her illness. The consequence of this effort is a feeling of "self" again: "*I exercised during chemotherapy while the doctors said you should not do it. I, by doing my activities, wanted to show that I was still alive (interviewee M)*".

3- In the redefining Identity strategy, after facing an illness crisis, people try to redefine the position of the body in their understanding, accept the illness identity as a part of their identity, and emulate the heroes who have won the battle against cancer, and reconstruct themselves: "*During treatment, I became acquainted with Lance Armstrong's book, and because my illness was exactly the same as his, and I can say that the book became the Quran of my life, that I did all the things he had done (interviewee M)*".

4- In the denial of illness identity strategy, one tries to reform and reconstruct the fracture and disruption of “self” by denying cancer and what has happened: "*From the day I realized that I was sick, I did my best to avoid*

anybody who has cancer. I do not want to, I did not want to accept at all that I am one of them (interviewee E)".

5- In the strategy of considering illness as a stage, regarding cancer as one of the stages of life, one tries to integrate this experience with other stages and periods of life, in this way to redefine the her/hisself life story: *"When I finished the chemotherapy, I cut my hair short and took a photo and posted a story on Instagram, telling all my friends, family and acquaintances that I was going to start the new stage of my life (interviewee L)".*

Quality of Self-Coherence. The quality of self-coherence explains the consequences that occur after experiencing self-disruption and applying strategies. By abstracting data, these consequences are defined in a range from adjusted to unadjusted coherence:

1- Adjusted coherence includes a set of healthy and adaptive consequences that lead one to believe that after cancer, her/his life has become meaningful and directional: *"Now I understand how much a person loves life. At that time, life was not valuable to me (interviewee I)".*

2- Unadjusted coherence is a set of non-adaptive consequences, and it seems that the survived person has a confused definition of "self" leads one to believe that her/his life no longer has a recognizable meaning and purpose: *"I no longer have the vivacity I had before, I have no previous mood. In this isituation, I'm isolated and bored (interviewee B)".*

Transitional Self-Disappear. This study developed the substantive model of "transitional self-disappear" to explain how people understand the “self” after getting cancer (see Fig. 1). This title was abstracted from the interviewees' descriptions and relationships between five major concepts. Indeed, Experiencing cancer and facing the issue of death makes people feel that the present time is a painful limbo that cuts the connection between the past and the future. That is, disruption is created in the temporary aspect of the self. This disruption and disconnection between the past, the present, and the future occur in various dimensions of understanding of self, including agency, physical, intrapersonal, relational and social, and emotional aspects. Therefore, in facing cancer, numerous aspects of experiencing and understanding the "self" are damaged and disrupted, and that previous "coherent and integrated self" is suddenly faded and lost. However this situation is not necessarily stable, rather self-disappear occurs transiently, meaning that self-disappear is an annoying but transitional stage to enter new and different conditions of life. And it is the result of self-regeneration strategies and occurs in the context in which one lives **(**cancer-based contextual experiences, and individual-environmental preparedness**).** The process of transitional self-disappear has been drawn in Fig. 2.

Discussion

This qualitative study was conducted to explore the process of change of self in people with cancer. According to the present study, at the time of an unexpected encounter with cancer, people experience a "temporal disruption"; meaning that they lose the sense of self-continuity over time. They suddenly think whatever they have built in the past is lost and there is no future to build. This is consistent with previous findings that show people with cancer expose existential challenges in their relationship to time [11]. Therefore, it seems that the sense of self that connects the past to the present and future of a person has disappeared.

Also, getting cancer is associated with some physical consequences (such as physical dysfunction, damage to beauty, the spread of illness in the body, the continued presence of the illness in the body, and so on), which

attack the person's previous understanding of his/herself. Probably the reason for such an experience is because the body becomes the center of attention and is considered by the person more than before, which changes the person's interaction with his/her body. Besides, following physical changes caused by cancer, people experience bodily doubt, and their previous assumptions about the relationship between the body and the "self" and their sense of wholeness are disturbed. Some previous studies [11, 13] also support this idea.

After the occurrence of such experiences of chronological disruption and body highlighted for the affected person, the sense of control and agency of “self” fades and is distorted. The patient, as a result of changes and losses in the experience of "self", is both confused and thinks that his/her life story is different from the life story of the person he/she was before and that his/her difference with others have proliferated because he/she is no longer an ordinary (normal) human being according to the definition of the culture and society in which he/she lives. One of the important experiences in this regard that has serious effects on the experience of "self" in chronic illness conditions is a change in a person's daily habits.

Because of these unpleasant experiences and social reactions to a person's illness, his/her relationships with others diminish or change, and he/she experiences cases like isolation and loneliness. Thus, consistent with the study [11], such experiences can impair the relational self, which is related to reciprocal interactions, intimacy, friendships. The study of Moore et al. [23] has shown that social isolation predicts the overall survival of patients with cancer. The sum of these experiences threatening the integrity and coherence of the "self", are associated with a range of unpleasant emotions (such as fear, anger, hatred, grief, and so on).

But the findings show that the journey of patients with cancer does not end here. Rather, self-disappear provides an opportunity for the sufferer to relinquish the understanding and narration he/she already had of him/herself, and by transcending from the living past and the imagined future, he/she reconstructs and redefines the "self". The experience of trying to reconstruct the identity of self by cancer survivors has also been reported in the study of Harkin et al. [12]. Patients with cancer try for self-reconstruction and use different strategies for this purpose. For example, make of theme and agency-seeking strategies can be ways to retrieve thematic coherence and retrieve the individual "self". Consistent with this finding, the results of Tiedtke et al. [24] on the return of patients with cancer to jobs show the importance of increasing the sense of agency in cancer survivors. Besides, redefining identity through the acceptance of cancer-related experiences as a part of the identity of "self" is used by survivors for a variety of purposes, such as reforming chronological disruption, reconstructing relational-self, and reducing over-differentiation. These strategies can be efficient or inefficient depending on the situation and the amount of use.

Ultimately, after a long period that people ignore their chronic illness, and know it insignificant, struggle with it, or compromise with it, they reach the sense of wholeness again, that is, the unity of "self" and the body versus loss [10], and they can experience self-re-coherence. Thus, self-disappear is not a permanent experience, rather it is a stage of transient, and each person experiences it under the impact of the type of strategies and the context of his/her experiences.

The context of the experience of patients with cancer and survivors can be examined at two general (overall) and specific levels. The general context includes characters and the previous coping strategies of the individual and macro-social conditions (including the individual's financial problems and the health system performance), that is not limited to the experience of cancer and the experience of transitional self-disappear but can affect

how to face it. But the context limited to experiencing cancer includes attitudes, conversations, and actions that are solely specific to cancer and the person with cancer.

Conclusion

There are few qualitative studies that have examined the process of changing various components of "self" in cancer survivors, and especially in the socio-economic conditions of Iran, no research has been done so far. However, the process of changing the "self" can determine the degree of adjustment of a person to new living conditions in the context of their lives. The rich data and findings obtained from this study led to the illumination of the quality of self-change of survivors and made the path they pass through clearer since the diagnosis of cancer. Also, the consistency of the findings with the theoretical and research literature indicates the accuracy and precision of the findings, which increases the reliability and the possibility to generalize the data. The findings of the present research should be interpreted and used with caution because although it was tried to examine as much as possible the diversity of experiences, But interviews with survivors were limited to a few specific types of cancer. In addition, Quantitative studies are suggested to test the findings and increase their generalizability.

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Figures

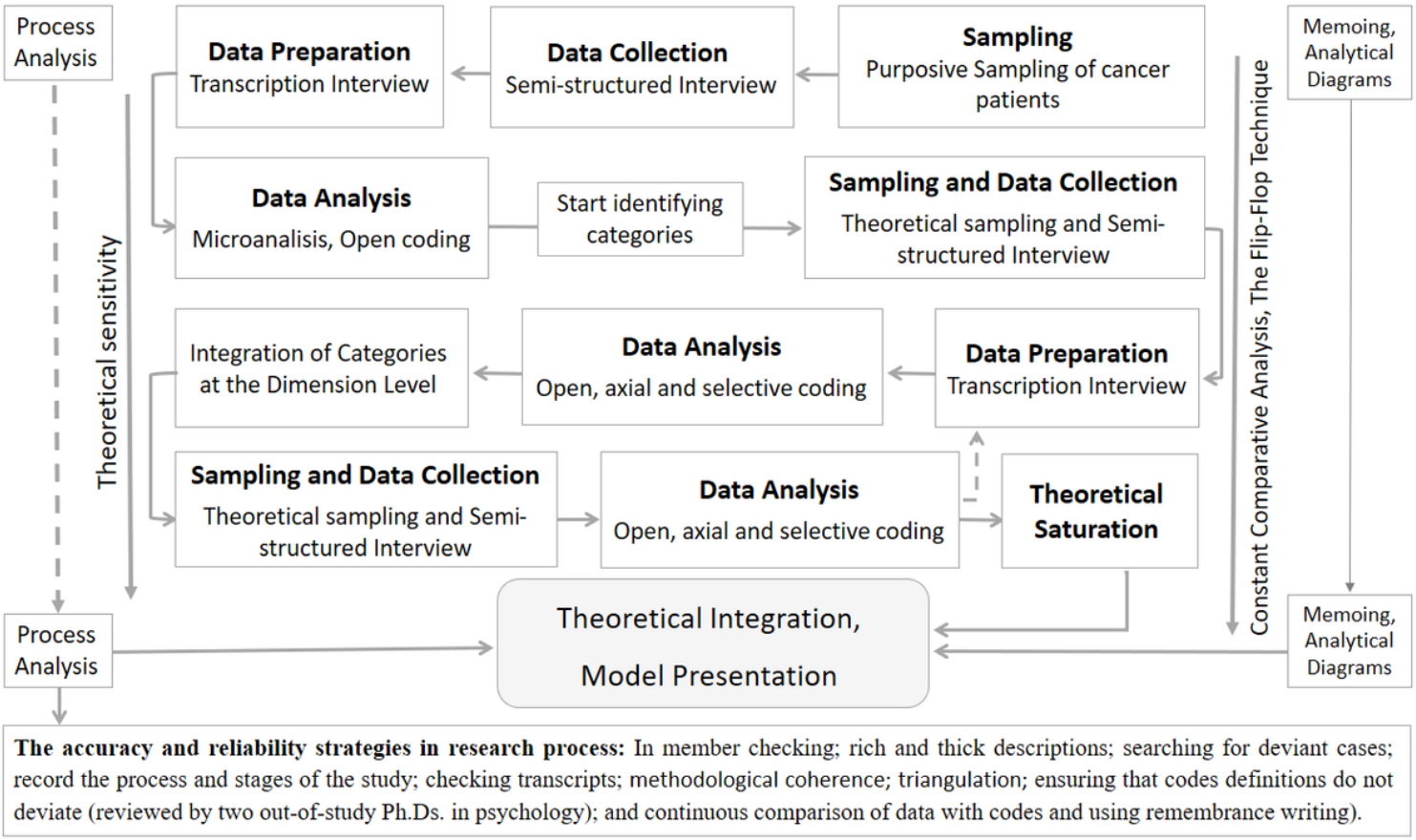

Figure 1

Visual representation of the research data collection and analysis process

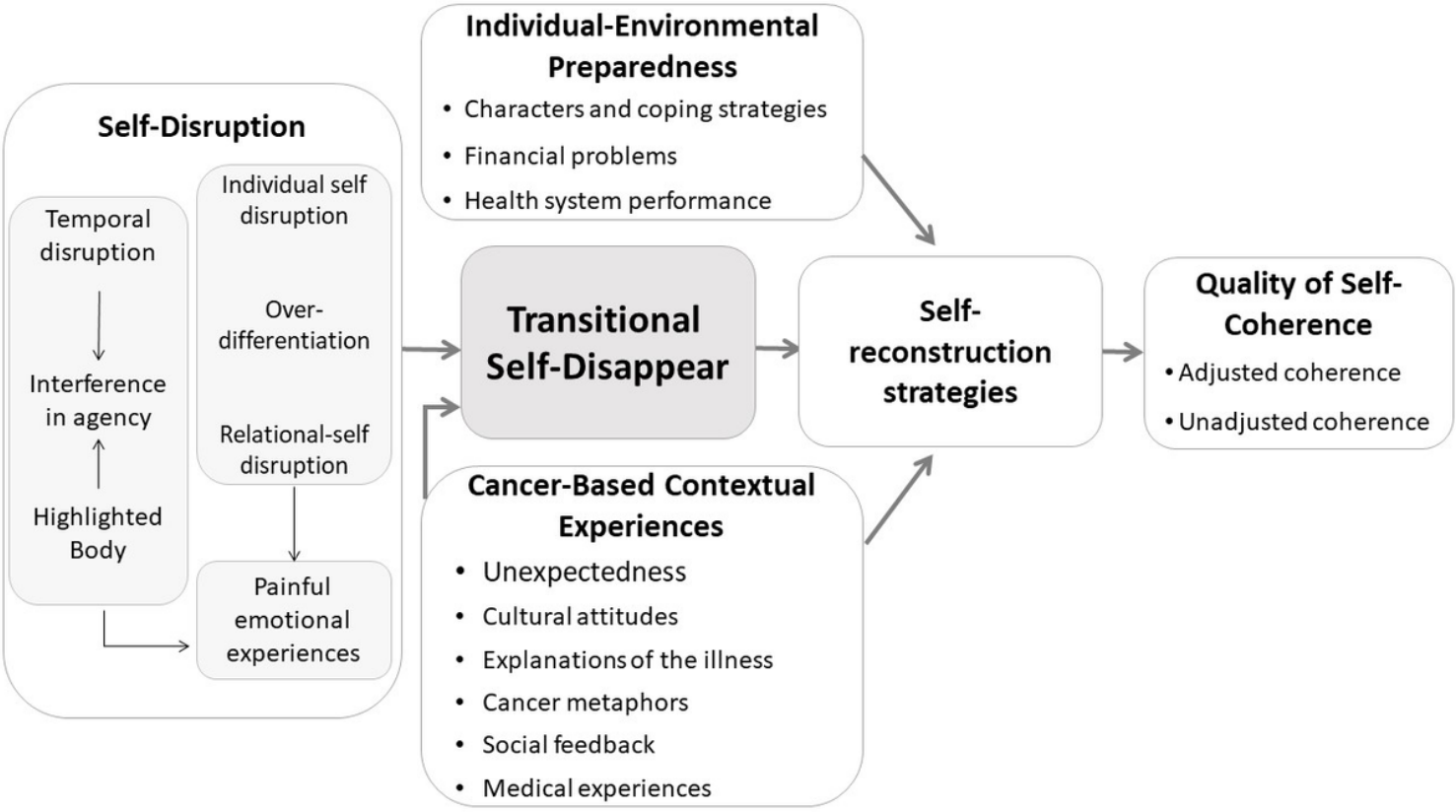

Figure 2

Model of "Transitional Self-Disappear" in the study of Cancer Survivors