

“Do I look pale?”

A therapist’s life-changing journey

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Abstract

The subject of therapists facing an illness or living with a health condition that impacts their practice hasn’t been addressed much. In my research I confirmed what I have been noticing in my practice as a systemic therapist: the relational space within myself, my thoughts, emotions, memories and embodied reactions, interconnects with the relational space between client and therapist. My inner voices, what I experience, feel and think (Rober, 2010) affect the way I connect to my clients. This means that when I am fully present with my various selves in the therapy room, more of the client is in there too. Therefore, when I was diagnosed with cancer, I chose to disclose my illness to my clients. In this paper, I discuss my experience with cancer, the way it had an impact on my practice and how I found a way to include the relational space within myself facing an illness in the therapy room. The story that is included in the paper is a story from within practice that appears in my doctoral thesis (Karamatsouki, 2020).

Greek (Ελληνικά)

Δεν αναφερόμαστε συχνά στο θέμα της ασθένειας ή των θεμάτων υγείας των θεραπευτών. Στην έρευνά μου επιβεβαίωσα αυτό που παρατηρούσα στη δουλειά μου ως συστημική θεραπεύτρια: ο σχεσιακός χώρος ένδον μου, δηλαδή οι σκέψεις μου, τα συναισθήματά μου, οι αναμνήσεις μου και οι σωματικές αντιδράσεις μου, αλληλεπιδρά με το σχεσιακό χώρο μεταξύ θεραπευόμενου και θεραπεύτριας. Οι εσωτερικές φωνές μου, το τι βιώνω, αισθάνομαι και σκέφτομαι (Rober, 2010) επηρεάζουν τον τρόπο με τον οποίο συνδέομαι με τους θεραπευόμενούς μου. Αυτό σημαίνει ότι, όταν είμαι εντελώς παρούσα με τους διαφορετικούς εαυτούς μου στη θεραπευτική συνεδρία, τόσο παρών είναι και ο θεραπευόμενός μου. Κατά συνέπεια, όταν διαγνώστηκα με καρκίνο, επέλεξα να αποκαλύψω την ασθένειά μου στους θεραπευόμενούς μου. Σε αυτό το άρθρο, παρουσιάζω την εμπειρία μου με τον καρκίνο, τον τρόπο με τον οποίο επηρέασε την ιδιωτική πρακτική μου, και πώς βρήκα τον τρόπο να συμπεριλάβω το σχεσιακό χώρο ένδον μου, ο οποίος αντιμετώπιζε μια ασθένεια, μέσα στη θεραπευτική συνεδρία. Η ιστορία που συμπεριλαμβάνεται στο άρθρο αυτό είναι μια ιστορία από τη δουλειά μου και έχει παρουσιαστεί στη διδακτορική διατριβή μου (Karamatsouki, 2020).

It's been twelve years since my diagnosis of Hodgkin's lymphoma, which is a type of cancer of the lymph nodes. Sometimes it feels so far away and at other times it feels as if it was only yesterday. At the time, I had a busy professional life, serving as a systemic psychotherapist in a center for children with developmental difficulties and their families, as well as having a part-time private practice. At the same time as navigating through medical tests and possible treatments, I needed to figure out how to navigate my ethical responsibilities to the people I was working with. Naturally, the question emerged: What do I tell my clients?

"Do I look pale?"

I am looking at myself in the mirror, trying to figure out if I look pale. Should I put on some more make-up? Finally, I shrug my shoulders and decide not to.

It's Wednesday, the day where I am going to have my first group therapy session after being released from hospital just a few days ago. I've been running this group for almost two years, but today I'm nervous. I have to tell them something and it's not going to be easy.

My co-therapist, Tatty, arrives with a box full of chocolates. It's her birthday today. Mine was three days ago. Until this year, we used to celebrate our birthdays together.

"Happy Birthday!" I wish her.

"Thank you!" she replies, and she gives me a warm hug. "How are you feeling?"

"OK, I guess. I'm kind of nervous. Do I look pale?"

"No, you look fine!" she reassures me. "And it's normal to feel nervous, to say the least! It's not easy." She looks at me with understanding. "Do you want to go over what we are planning to say one more time?"

I nod, thinking how grateful I am that Tatty is both my co-therapist in the group, as well as one of my best friends. We chat for a bit longer and then I make some coffee.

When our clients arrive, I have the feeling they are all looking at me, trying to understand if something is wrong. I also have the feeling that my behaviour reassures them; I might not look so pale after all...

My co-therapist and I have decided that we will talk to the group at the end of the session. This way, we will address the issues each member brings to the group and will avoid making their therapy session about us... or rather about me. We go about the group session as usual.

Although a part of my brain is preoccupied with what I want to say to the group, I am surprised at how my professional self takes charge once the session begins. I love my work and I especially love working with groups. The dynamic flow of a group session, especially of a group like ours, whose members have been working together for a long time, is mesmerising.

After everyone has spoken, even for a brief check-in, I take the lead.

"There are two things that we would like to tell you today," I say to the group. I sense my clients' unease; they shift on their seats and glance quickly at each other. Then, as agreed, Tatty continues.

“First, it’s my birthday today and I brought some chocolates for all of us to share.”

As she goes to get them, everyone wishes her Happy Birthday. I wait until everyone gets their chocolate before I continue.

“You all know that I cancelled last week’s session, because I was at the hospital for some medical tests,” I start slowly. “Well, these tests showed that I have lymphoma, cancer in the lymph nodes.”

There is a silence and I wait for the information to sink in. I heard myself saying the C-word, my clients’ eyes wide open, fixed on me. They are shocked, I suppose; I know I would be, if I were in their shoes. My heart beats fast and I try to keep my voice steady. I had a supervision session a couple of days ago, where I rehearsed what I was going to say and choose my words wisely. I understood what it would mean for my clients. I knew that they were going to be worried about me and wonder how I was doing. I knew they would be afraid I was going to die - I was afraid I was going to die, too. I also knew it was not going to be an easy process. Still, I didn’t hesitate. Other therapists might have chosen not to disclose their illness. One colleague, in particular, told me that, if she were me, she would tell her clients that she needed to take some time off work, without giving them a reason. “It’s not their job to know”, she said. But I knew what was the right thing for me to do, the ethical thing for my clients and myself. Anything less than the truth would make me feel like I was lying to them - and to myself. I take a deep breath and continue.

“I will start chemotherapy in a couple of weeks and the doctors are optimistic. It’s a kind of cancer that has a good prognosis and the chances are I am going to be fine.”

I sense the group members start to breathe again after holding their breath for a while. Their eyes are still fixed on me, as if trying to understand more behind the words they are hearing. Some of these eyes are watering and a hand reaches for a Kleenex.

“I know it’s going to be difficult for all of us. I struggled with how to tell you about it, but I decided that the ethical thing to do is to tell you the truth. My plan is to continue working, as long as I can, but I may have to reschedule sessions, if I need to do some more medical tests. And I didn’t want to lie about why I need to reschedule.”

All heads nod and I can hear some voices saying “of course” and “you did the right thing”, which reassures me that I am on the right track.

“Having said that, however,” I go on, “I know you are going to worry about me and wonder about how I am doing. Maybe there will be days when I will be more tired; I don’t know yet how the treatment is going to affect me.” I take another deep breath before I continue because what I am about to say next is really painful for me, and I need to keep a steady voice. “You should also bear in mind that my appearance might change. The doctors said that I will probably lose my hair because of the chemotherapy.”

I remind myself that it’s not the time to think about hair loss now, but it has been on my mind ever since the diagnosis. I love my long, wavy hair and the change in my self-image will be enormous. Still, my professional self takes charge: I am talking about my clients’ therapy now.

I look each one of them in the eyes before I go on. My voice is steady. “I want you to know that I am still your therapist and that I will try my best to protect your therapy. You can discuss absolutely anything you need to about my cancer with me and I will try to be open about it.”

I turn to look at my co-therapist. She nods encouragingly and I continue.

“However, I also understand that it might be difficult to raise such an important topic with me if you are worried about my health. So, there is always an option that you can talk to Tatty, if you feel more comfortable.” Tatty looks around at the group and nods emphatically. “And of course, there is always a chance that this whole situation is too much for you and you might prefer to find another therapist to work with. Remember, it’s about *your* therapy and you need to decide what’s best for *you*. I completely understand and I will be happy to make a referral if that’s the case.”

Saying this last part was quite painful for me. I know I would be hurt if a client decided to discontinue therapy with me because of my cancer. But I truly meant every word I said: it was *their* therapy and they had every right to make the choice that felt right to *them*.

I take a deep breath. The hard part is over. Now let’s deal with the consequences.

“I understand how difficult this must be for you,” I say looking around the group. “You are trying to work things out in your life and your therapist is diagnosed with cancer!” I roll my eyes, trying to lighten things up, and see a few smiles. I smile back.

“But, you know, as we have discussed so many times before in the group, life is like that. Bad things happen all the time and I am no exception. And there are good things, too. Today we celebrate Tatty’s birthday, which is important. And sometimes, good news and bad news coexist, like today. That’s life.”

The group members seem more relaxed now. I certainly feel more relaxed. I also feel exhausted and I hope I don’t look pale. I look at my co-therapist and smile. She smiles back. It’s like we are saying to each other that it went OK.

“This is something that will come up again in future sessions and you might need to discuss it further,” I say. “For now, is there anything you want to say? Do you have any questions? Do you want to share a feeling or a thought? We are here to listen to you.”

Behind the scene

At the time of my diagnosis with cancer, I was working two days a week as a systemic psychotherapist in a center providing therapy to children with developmental difficulties and their families in a suburb of Athens, Greece, doing parents’ counselling, family sessions and individual psychotherapy for children and adolescents. The rest three days of the working week I was beginning to establish my private practice, working with individuals, couples, families and groups. The decision to disclose my diagnosis therefore was impacted by my work context. In the therapy center for instance, I was hesitant to disclose my diagnosis to the children and adolescents I was working with, because of their developmental status. In a fortunate coincidence, as I was beginning to focus on my private practice as well, before my diagnosis, I had started referring children and adolescents to a colleague in the therapy center, and I had decided to continue working with their parents and do the family sessions. I was relieved that I would no longer work with children, as I feared that if I died, the impact the death of their therapist would have on them would be immense.

I did disclose my diagnosis to the parents I was working with, however, and helped them answer their children's questions, in case they asked something like why I was wearing a headscarf.

In my private practice, I had no contextual dilemmas of this sort. Although I was aware of the uncertainty the disclosure of my diagnosis would have on my clients, I did not have any second thoughts. I discussed the complexities of my self-disclosure with my clinical supervisor, who helped me a lot to find my way through being in the haze of a diagnosis of a life-threatening illness and still be a focused and competent therapist. In addition, working with another therapist, who also happened to be a good friend of mine, added clarity to the confidence of acting ethically by self-disclosing. Being part of a team in the therapy center was also very helpful in that term, and all my colleagues there supported my decision around self-disclosure.

The inclusion of the relational space within the therapist in the therapy room

Systemic therapists vary in their perspectives on how much transparency, openness and self-disclosure on the therapist's part should be included in the therapeutic relationship. For instance, Janine Roberts' work (2005) includes the dangers as well as the possibilities on the therapist's self-disclosure and transparency. Every therapist makes the decision about how open and transparent they want to be, depending on their theoretical orientation, their personality, their client, as well as the context of the conversation. Systemic therapists acknowledge that self-disclosure is unavoidable, even if it is used only in joining the client and to a limited degree (Roberts, 2005). As a therapist, I self-disclose information and I am generally transparent with my clients, considering of course that it is their therapy. This becomes particularly clear in this story (Karamatsouki, 2020).

However, this story is more than the self-disclosure of a therapist. As a systemic psychotherapist, I bring to the session not only my professional self, but also the voices of my personal selves, moments with my family of origin, culture, personal beliefs and values, current difficulties in my life, and my thoughts and feelings, all of which create the relational space within myself (Karamatsouki, 2020). My inner voices, what I experience, feel and think (Rober, 2010) affect the way I connect to my clients. In my research, I confirmed what I have noticed all these years that I have been working as a therapist: when more of myself is in the therapy room, more of the client is in there, too. Therefore, I chose to be fully present with my various selves in the interaction with my client, because when I bring all of myself in the therapy room, it makes a difference in the therapeutic relational space (Karamatsouki, 2020).

When I was diagnosed with cancer, it never crossed my mind that I would quit working as a therapist, provided of course that I felt well enough. Therefore, I decided to take Fridays off and arranged to do my chemotherapy sessions on Friday, so that I would have time to recuperate during the weekend and go back to work on Monday. Being a therapist has always been an important part of my identity and since I would continue working as a therapist, I chose to disclose my health condition, keeping in mind my clients' best interests of course. This decision was based on relational ethics (Gergen, 2015), as, when I disclosed my cancer to my clients, including the therapy group I run, at the same time I was committed to protect the therapeutic relationship. For me, it would be unethical to try to keep such an important part of myself, the part that was facing a life-threatening illness at the time, hidden from my clients. During that time, the relational space within myself included my professional capacity to hear and hold my clients' own needs and their responses to

me, as well as my thoughts and emotions of dealing with my cancer. I wrote in my thesis, when discussing the ethical implications of my research (Karamatsouki, 2020, p. 139):

“I made the decision to disclose my cancer diagnosis, which is a decision that other therapists might find boundary-violating or even unethical, but to me it felt like an ethical decision. For me, good practice means that I am open and honest with my clients, but at the same time I keep their therapy in mind. I choose to speak a truth that other professionals would avoid speaking of, but I choose to do it in an ethical and reflexive manner.”

My decision to disclose my diagnosis of cancer brought a messiness in the psychotherapy process. But isn't psychotherapy a messy process anyway? Storywriting has helped me navigate through the complexities that happen in the therapy room, especially in a time when a diagnosis with a serious illness came in the foreground.

Autoethnographic storywriting

In my practice, as well as in my research, autoethnographic writing helps me capture the relational space within myself. Autoethnography is “an autobiographical genre of writing and research that displays multiple layers of consciousness” (Ellis, 2004, p. 37). For me, autoethnographic storywriting punctuate moments in therapy where the not-yet-known becomes part of the process (Karamatsouki, 2020). As such, writing stories has also helped me make sense of what happens in the relational space within myself during the time around my diagnosis with cancer and subsequent treatment.

“In this story my vulnerable self takes over the relational space within myself in several occasions, for instance when I announce the results of my medical tests to the group, or when I warn them that my hair might fall out and my appearance might change. Even in these occasions, however, I never forget my professional self who has the responsibility of taking care of my clients' therapy. Although my inner dialogue hovers over the therapy session, I am able to use the relational space within myself in a way that is beneficial to my clients and opens up opportunities for change.”

(Karamatsouki, 2020, p. 189-190)

I wrote this story a few years after that particular session, based on my reflexive clinical notes, on my reflexive diary and on conversations with my colleague and friend, Tatty, who also read the story and offered feedback. I was thinking about this incident for quite some time and I felt I needed to get this story out there, so that I can make sense of events. This process often happens before I write a story, which I use as a learning opportunity.

In my practice and in my research, storywriting has been a way to talk about things that we don't usually dare to talk about in our profession, such as the subject of therapists living with an illness or a health condition. Most of the stories I write, including the story that is featured in this paper, are about relational ethics and decisions I need to make as a systemic therapist during therapeutic

interactions. In an honest and reflexive manner, I tried to give readers insight into the processes that happen in the therapy room. I wrote about my cancer diagnosis and how I used the relational space within myself during that time in the therapy room in order to gain a deeper understanding of myself and my practice. During that process, I found helpful to read other systemic therapists' dilemmas around self-disclosure and transparency. In a paper she wrote with her dying partner, Liz Day wrote:

“How do therapists create conversations that navigate complex and difficult situations and life events and give meaning to them? How do we make and retain our connectedness? Adversity doesn't only happen to our clients; it also happens to us. Experiences that cause us pain and distress have the capacity to create resources for us. Learning to steer a way through choppy and treacherous waters can equip us to manage threatening situations with a greater sense of agency. When we are “at sea”, we need points of connection to steady things and anchor ourselves. These points of connection can be friends and colleagues, but they are also provided by texts and through mapping the network of theoretical knots and intersections.”

(Day & Charing, 2018, p. 36)

With this paper, as with most of my writings, I have the hope that practitioners will be encouraged to open up conversations and share their learnings, as each of us allows themselves to include their inner voices in the therapy process.

Then and now

While I was writing this paper, I revisited some of my personal writings from the past, particularly from around the time I had finished treatment for my cancer - chemotherapy and radiotherapy sessions – things that I have forgotten I have written.

“That period, however, also felt like something deeper was happening to me. Not only the cancer had gone, but something else made its appearance. It was a part of me I knew it existed, but since then did not give much attention to. This part first presented itself in a dream. [...] When I woke up in the morning after this dream, I was feeling optimistic and at the same time fearful. [...] (W)hat was this part? How can I be more in touch with it? I knew that this part had something to do with my cancer and I believed that being in touch with it would protect me against future threats.” (Personal writings from 2012)

This excerpt from 2012, in which I refer to parts of myself, made me realise that years before my doctoral research I had already conceived the concept of the relational space within myself. Reading these writings again reminded me of how my body reacted at that time; I even felt nauseated, like during my chemotherapy sessions. It's strange how memory works and how bodily reactions are triggered with certain stimuli. As a systemic therapist, I have always paid attention to embodied responses in the therapy room. In addition, during my research, embodied responses were an important part of the relational space within myself, and I dared to pay attention to and talk about them. When a client talked about her mother's diagnosis of breast cancer, I felt the fear and agony in my chest, as on the day I received my diagnosis. Instead of being afraid though, I used the

relational space within myself, in order to respond to my client in a professional way with empathy and concern, despite my emotional reactions.

“The way the relational space within myself appears in my stories challenges the idea of unwelcomed responses in the therapy room and raises questions about whether the therapist can be prepared with prescribed interventions. This means that psychotherapy is not a static process. As such, the relational space within the therapist enters the therapy room without the therapist having a clear idea of what is going to happen. What my inquiry suggests is that the relational space within the therapist cannot and should not be silenced, as it can be a useful resource for the therapy, contributing to the creation of relational ripples.”

(Karamatsouki, 2020, p. 200)

My experience with cancer affected me as a person and as a therapist, and it also affected my practice. In order for me to do my treatments and medical tests I cut down on my working hours and declined new referrals. I experienced side effects from the chemotherapy and at times I felt tired. As I got further into treatment, I could see some of my clients worried more about me, although I stayed positive and led an active life. Some of them asked me how I was doing and I answered honestly that I was doing OK and tried to stay positive, although at times I was feeling tired. Some others hesitated to ask me and avoided mentioning my illness, although I could sense they were worried about me, and I kept them updated in the same way I described. When my hair started to get thinner and I eventually lost it, I started wearing headscarves. Although I had warned my clients about the potential change of my appearance, I could see the startled looks on their faces. Eventually, as I showed I wasn't avoiding the issue of my illness and I was open about it, themes that related to my cancer and my clients' worrying about me came up, and I did my best to address their concerns in a therapeutic way that would help them – and me – go forward. For instance, in a particularly moving session a client asked me how I always showed so positive and full of life, despite what I was going through. I noticed she deliberately did not say the word cancer.

“Although I try to be, I am not always positive, especially on chemotherapy days, when I am more tired,” I answered with honesty.

She hesitated for a moment and I started wondering whether I had disclosed too much.

“I guess a part of me already knew the answer,” she responded. “But I needed to hear it from you that you also have bad days. Because otherwise, it feels unreal that you seem so well and still have...” she stopped.

“Cancer,” I finished her sentence. “Yes, sometimes it feels unreal to me, too,” I admitted. “The truth is most of the time I focus on positive things, which makes me feel good, so what you see of me being positive is actually how I am feeling.”

She nodded. “Thank you for being honest with me.”

My professional self wanted to make sure I attended to my clients' needs, so I increased the frequency of my clinical supervision sessions. I made arrangements with a few trusted colleagues about what to do with my clients' records and clinical notes, how to inform my clients and to whom my clients could be referred in case I die. Thinking about the possibility I might die though, made me focus more on life, my life and my clients' lives, and I believe it made me a better therapist. My experience with cancer enabled me to embrace my different selves, including my vulnerable self, the part of me that was afraid I might die, and allowed me to use the relational space within myself as a resource in the therapy room. Although my cancer is in remission for eleven years now – and I am considered cancer-free – I can still feel the experience of living with cancer vividly. This happens not only because my emotions at the time were intense, but also because of the learnings I hold, learnings that I can utilise as a therapist.

Now, when something unexpected happens in the therapy room, I find a way to stay with my uncomfortable feelings, focus on my self-reflexive skills and trust myself and my client that we will navigate through the process, as the story describes. The relational space within myself evokes my experience as a therapist and dictates my professional responses (Karamatsouki, 2020). It can also be unpredictable, in the sense that it unsettles the situation in the therapy room. By including all of myself in the therapeutic conversation, I create a professionally employable space for the personal and show how therapy can be done differently (Karamatsouki, 2020). It is noteworthy that, although I gave my clients the option of referring them to a different therapist, they all continued therapy with me. This strengthened my belief that “when the therapist brings more of themselves in the therapy room clients feel more connected to their therapist, the therapeutic relationship becomes stronger, clients find therapeutic conversations more helpful, and thus they are more likely to make changes in their lives” (Karamatsouki, 2020, p. 213).

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