

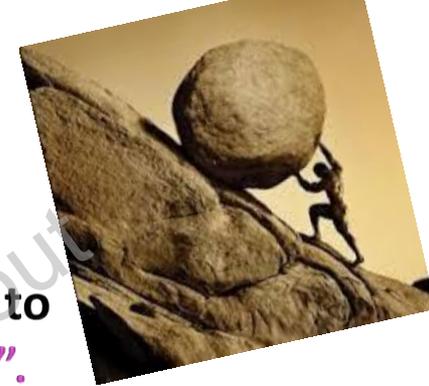
BCY4

Support groups in the post treatment phase

“The beauty from the dust”

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Distress induced by experience with cancer



“The diagnosis of a cancer is a threat to the life, and a threat to the “thinking”.

(Jimmie Holland, S. Lewis, The human side of Cancer, 2000)

“Young women have been documented to be at greater risk of psychosocial morbidity after a diagnosis of breast cancer. ”

(ESO-ESMO 3rd international consensus guidelines for breast cancer in young women, BCY3, The Breast, 2017)

Breast Cancer in young women:

- **Not frequent** (“**Nobody** can understand my disappointment, my anger”)
- **High emotions** grow inside, expressed in a non verbal way and often “against” family members
- **Coping skills** require a lot of energy normally employed in other tasks of life (career, marriage, children, relationships,...) and induce **distress**.

Assessment of emotional distress

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COMMENTARY

2015 President's Plenary International Psycho-oncology Society: psychosocial care as a human rights issue—challenges and opportunities

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- Distress should be mandatorily measured as the 6th Vital Sign
- 30-40% patients present emotional distress not only at diagnosis but also during treatments and need support
- Distress may interfere with the ability to cope, to accept medical care, and need to be treated

Treatment of distress

“Patients' distress and psychosocial needs should be regularly assessed. Psychosocial care should be available and integrated in routine cancer treatments and follow-up.”

(ESO-ESMO 3rd international consensus guidelines for breast cancer in young women (BCY3, The Breast, 2017)

Psycho-oncological interventions:

- **Individual Psychotherapies:** cognitive-behavioural therapies, cognitive-analytic therapies, supportive psychotherapy, systemic-relational approaches
- **Couple Therapies:**
“Relatives suffer even more than patients, often in silence, and require specific supportive care” (Baider, 2000)
- **Family Therapies:** focus on the complexity in relationship and communication inside the support system, in order to find a new adaptive balance for all the family members

In PO individual setting, BCY patients report:

*“Women receive a lot of **support** from their family, friends and health care providers during the period **closer to diagnosis**. Receipt of helpful **support drops** significantly **within the first year itself**.”*

(Arora et al, 2007).

- the **sword of Damocles** hang over their head even if BC is at an early stage or curable. Negative feelings are inevitable (fear, anger, guilt, sadness,...)
- **negative feelings** are difficult to share with friends and relatives especially at the end of active treatments or later
- “Positive attitude”, “leave the fears behind”, “you are healed” are sentences who **close the communication**
- to feel alone, with emotions and thoughts left inside for fear not to be understood from “healthy” people, exacerbate the sense of **isolation**

BC induces a disruption with the previous life

- **Sense of vulnerability:** inadequacy, fragility
- **Body becomes unfamiliar and damaged:** scars, mastectomy, hair loss, lymphedema, fatigue, gain of weight, pain, fatigue, vaginal dryness, broken nails, eyelashes loss
- **Change in self image:** “I’m alive but it’s difficult to recognize me, I was young and I feel ugly, tired, old”
- **Loneliness:** difficult to verbalize with others
 - Do you know women in same situation? What they do?
 - How they manage emotions, loneliness and marginalisation?

Could it be **useful** to get over this deep emotions of loneliness and misunderstanding in a **group of women in similar situation**?

Normal reaction to abnormal situation

*“For women with breast cancer, **sharing these experience** and hearing the stories of other women can help to put their own history into **perspective**.*

Thoughts and feelings that originally seemed aberrant become normalized and easier to accept”

(Spiegel, 1979)

Group Intervention: history and leaders

- In **1905** medical doctor in Boston, **Joseph Pratt**, created the first formal therapeutic group, when he brought together 15 of his **tuberculosis patients** in order to educate them about the disease and allow them to discuss their common problems
- Other early pioneers, established **experimental groups** for psychiatric, neurotic, physical ill patients, distress soldiers, alcoholics, disturbed children and so on. (Lazell, MetzI, Burrow, Adler, Dreikus, Slavson, Bion, Lewin, Eziel, Foulkes, Whitaker, Lieberman and Yalom)
- After **1960** the group intervention became common also in **Europe**

Psycho-oncology Group Therapy Interventions

Many studies show positive effects of GTI for cancer patients:

- **Improve coping skills** (Turns, Fawzy, Cousins, Spiegel, Bloom)
- **Reduce anxiety, denial, distress and depression** (Spiegel, Kissane, Sheard, Maguire)
- **Improve psychological wellbeing, QoL, trust in personal resources** (Fawzy, Grassi, Gunn, Galway, Zainal, Johannsen, Barrera, Spiegel)
- **Reduce side effects** (Forester, Cain, Morrow)
- **Improve adherence with medical treatments witch may prolong disease-free and overall survival** (Spiegel, Motzer, Geller, Hoagland, Morrow, Steckel, Harris, Lippman, Richardson, Shelton et al.)

Group therapy is now recommended as a component of standard treatment for BC.

Models of Group Therapy Interventions in PO

- **Psycho-Educational Intervention:** especially after recent diagnosis. Aim to replace chaos with internal control to manage distress and improve problem solving skills (Jacobs 1983, Fawzy, Fawzy 1990, 1993, 1994, 2003, 2011, Cunningham 1989, 1995, Helgeson 1999, Fukui 2000, Taylor 2003, Maeda 2008, Dolbeault, Cayrou, Bredart 2009, Capozzo 2010)
- **Cognitive Behavioural Intervention:** short intervention during or at the end of treatments to ameliorate coping through several techniques including information, imagery and relaxation (Greer 1992, Watson 1996, Kissane 1997, Fawzy 1997, Simonton, Sherman 2000, Baider 2001, Bianchi, Tomamichel 2005, Horne, Watson 2011, Johnson 2016)
- **Supportive-Expressive Intervention:** long period open group, to help members accept illness and life vulnerability step by step to find a sense and manage mood disturbances (Yalom 1980, Spiegel 1981, Spiegel, Classen 1999, 2000, 2008, Spira 1998, Goodwin 2001, Kissane 2003, 2007, Grassi 2010, Breitbart 2015, Van der Spek, 2017)

Evidence for effectiveness of GTI

- **Psychosocial wellbeing:** most studies suggest an increase of QoL, adherence to medical treatments, coping skills and a reduction of distress, psychiatric and somatic symptoms (Fawzy 1999, Weis 2003, Gottlieb 2007, Grassi 2010, Gunn 2011, Galway 2012, Zainal, 2013, Johannsen 2013, Barrera, Spiegel 2014, Hunter 2017)
- **Survival:** Controversial data.
“Women with metastatic breast cancer lived an average of 18 months longer if they participated in supportive group therapy” (Spiegel,1989).
Fox (1998) and other authors didn't find similar positive outcomes in relation with survival. Spiegel (2007) didn't replicate the same results in a successive study, neither Kissane 2007, Andersen 2008, 2010, Giese-Davis, 2011, Wayne, 2016.

Optimal timing for joining a group

The initial **diagnosis** and period immediately after initial **treatment ends**, are times of special **distress** (Holland, 1989, 2011, Fobair, 1986).

Providing **group support** after medical treatments have been completed, helps patients come to terms with emotional aftereffects of the illness (Spiegel, Classen, 2000).

The **period after the medical treatment ends** appears to be the optimal time to:

- **Consult psycho-oncologist**
- **Join a group**



Anna dai Capelli Corti: Supportive - Expressive Group for BCY



Since 2016, the Group ACC offers an opportunity to meet together after the initial oncological treatment ends (CT and RT) for:

- **Women younger than 50**
- **Target:** single cancer population BCY, open group, not time limited
- **Multidisciplinary team** (1 psycho-oncologist, 1 nurse, 2 oncologists, 1 radiologist) of the Southern Swiss Breast Centre
- **Goal:** the group should become a place of mutual support, listening to one another's thoughts and feelings difficult to avoid even in individual consultation (altered sexuality, loss of certainty, feelings of loneliness and abandonment, threat of recurrence and death) in order to enhance self-esteem and confidence in coping with BC

Aims to achieve



- Tackle the **specific needs** of breast cancer patients under 50: fertility, care for young children, professional career, new couple challenges
- **Encourage the expression** of thoughts, doubts, fears and **face** them together, in a supportive atmosphere, **rather than avoiding them**
- Join a better and deep level of awareness about **feelings**, but also **ability** and **strength**
- **Mirror experience**: learn new adaptive strategies from peer interactions
- Support young women to **regain self-esteem** and to find a new psychosocial and physical **balance**
- **Fundraising** in order to support research projects, increase community knowledge and awareness about BCY

We offer different **opportunities** to exchange experiences, problems and solutions:

- **Physical activities:** Promote rehabilitation by organising meetings to approach the transition from sickness to health (physical and mental)





- **Cultural activities:** conferences or courses about topics related to BC (emotional status before medical control, nutrition, sexuality, long-term side effects, pregnancy after BC)





- **Activities open to the community:** conferences to deepen topics, Fundraising events to raise money for further research projects



Research projects supported: 2017

Video to promote the IBCSG POSITIVE Study: which evaluates the safety of interrupting endocrine therapy for BCY who desire pregnancy.

App CSSI: for smartphone created by Dr Med **Francesco Meani**, CSSI, and Dr Med **Giacomo Montagna**. Permit to collect the clinical documents and organize the appointments through a shared agenda.



Projects supported in 2018

Side effects:

- 2 days course “Managing side effects” with Christine Boers-Doets, founder of CancerMed, NL
- 3 afternoons about specific topics: nutrition, vaginal dryness, complementary therapies

Fencing: pilot project Vales for BCY few months after surgery



Challenges



- Navigate together into the complexity of BCY
- Reduce shame or fear associated with certain topics (intimacy, sexuality, damaged body, recurrence or death)
- Destabilize rigid beliefs and avoid judgments, which close the communication and freeze the relationships
- Encourage open communication, also with relatives and healthcare providers
- Assume responsibility for thoughts and attitudes, with courage and pride, to co-create a shared lecture of the complexity
- The group must remain safe and respectful: a member shouldn't emotionally hurt nor be hurt by the group

Difficulties for conductors

- **“Prison of positive thinking”**, it is good to have a positive attitude but it is undeniable to have negative feelings emerging, which should be allowed to be acknowledged and not rejected
- **Personality traits:** (difficulties in forming alliances, unrealistic expectations, aggressive judgements, need of supremacy, open or hidden hostility) may interfere in the group relationships and need to be identified and managed by conductors
- **Triangulations** inside the group are dysfunctional (emotional Tsunami)
- Conductors have to think in advance how to protect the boundaries and **restore communication** if emotions become source of suffering for one or more participants
- 2 conductors should always be present to reach **rapid contextualization**, leave the acting-out and maintain a cohesive group climate

Multidisciplinary Team (oncological and psychosocial fields)

MT conductor is a part of the group system and has to:

- have **knowledge** about illness and treatments
- be **flexible and pragmatic**
- keep watch over all exchanges
- **legitimize all emotions**
- be able to **face** rapidly **emotional drifts**, without underestimate them
- mediate between **herself/himself and the group**
- go inside the complexity with **curiosity**, in order to co-create with the participants alternatives meanings and imagine a new balance



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Group intervention

- Improve QoL
- Enhance coping
- Manage distress
- Provide a significant emotional support
- Increase communication with relatives
- Enhance intimacy
- Decrease loneliness
- Improve mutual comprehension
- Cost-effectiveness

The beauty from the dust

“Human emotions are universal and unchanging – only medical treatments change” (Lederberg, Holland, 2011)

- **“Anna dai capelli corti”** is challenging in our reality but could be also useful to be exported in others contexts, too
- **Multidisciplinary team**, is required to manage behaviours and emotions resulting sometimes abruptly from apparent trivial situations
- **Implementation** and dissemination of guidelines about Group Intervention, improve knowledge in prevention of distress, communication, collaborative relationships with healthcare providers and increase the sense of inclusion in “a larger whole” (Yalom, 1980).



Thanks
for your
attention

