GMR
The Original

COMMUNITY LIVING - A SENSE OF BELONGING, FRIENDSHIP, SUPPORT AMONG CANCER PATIENTS IN PALLIATIVE CARE

Dr. Leuca Smilee V[1], Dr. Pandab Hansda[2], Dr. M. Amirtha[3], Mrs. Gayathri Devi S[4], Ms. A. Devaki[5], Ms. Hemavathy V[6]

[1]Assistant Professor, Department of Social Work, Hindustan College of Arts & Science, Chennai, Email-leucasmilee@hcaschennai.edu.in,
2Assistant Professor, Department of Social Work, Hindustan College of Arts & Science, Chennai, Email- pandabhansda75@gmail.com, 0000-0003-0633-5461
[3]Head, Department of Psychology, Hindustan College of Arts & Science, Chennai, Email: hodpsy@hcaschennai.edu.in
[4]Assistant Professor, Department of Psychology, Hindustan College of Arts & Science, Chennai, Email-gayathridevihcaschennai@edi.in
[5]Counsellor cum Lecturer, Department of Psychology, Hindustan College of Arts & Science, Chennai, Email-devakiarapathi0310@gmail.com
[6]Lecturer, Department of Psychology, Hindustan College of Arts & Science, Chennai, Email-hemavelu1234v@gmail.com

ABSTRACT
This study indicates community living as an effective means to cope with cancer. This article points out the way of living of cancer patients in palliative care and how they cope with their illnesses. They live in a community setting, and their community living helped them cope with the symptoms and become self-aware and expand their knowledge of the illness. The friendship that bloomed in the course of time offered great emotional strength and motivated them to overcome the illness. This group is formed by themselves without any professional interference. Therefore, the article suggests that the social worker, who is professionally trained to help them navigate both the group and the treatment trajectory, intervene. To conclude, support groups and living as a community act as a means of catharsis for the patients.

KEYWORDS: Emotional strength, Catharsis, Cancer Support groups, Community Living, Coping Strategies.

INTRODUCTION
Cancer is one of the life-consuming illnesses. People affected by it suffer from physical, psychological, and relationship issues, which are expected to be treated holistically. Rather, in hospitals, the physical aspect of the illness is concentrated more, and the rest is not treated with proper professional support, which in turn burdens them. In 2024, 2,001,140 new cases of cancer and 611,720 deaths from it were observed [1]. Cancer rates are rising each year, and professionals treating them holistically help them greatly. Apart from professional help, cancer patients tend to help each other and access support among themselves by simply chit-chatting about their struggles and how they overcome certain symptoms. Especially in palliative care centres, they tend to spend a lot of time with other patients, and they stay there for a longer period of time, until they manage the symptoms. Living as a community and helping each other at times of distress creates a sense of belongingness, which offers them great emotional strength from the people who already suffer from the illness.

REVIEW OF LITERATURE
Support groups help cancer patients improve their quality of life in a psycho-social context. The theory of community living emerges from the Social-cognitive processing theory, which implies a positive relationship between the social environment and cognitive processing. A positive, supportive social environment among cancer patients helps them to adjust emotionally to the illness. This helps them to reflect on their inner self without judgment and express their thoughts and feelings about cancer. support groups support them socially and emotionally in a controlled environment, helping them to cope with the illness through altering their attitudes, knowledge (Fang-Yu-Chou, 2016). Support groups offer a sense of control and increased confidence amidst living with cancer, whereas support from family will be viewed more as sympathy and a burden. Support groups offer a safe space for catharsis, and the need for family to take up the entire burden of handling both the physical and emotional turbulences of the patients is shared by the support groups (Jane Ussher, What do cancer support groups provide which other supportive relationships do not? the experience of peer groups for people with cancer, 2006). The patients in cancer support groups demonstrated a mutual understanding of the illness that one another can understand, and they exchanged a strong sense of belonging and a unique sense of bond in an open, non-judgmental environment. However, one disadvantage of these groups is the potential for negative impact on members, particularly when a member dies during the treatment trajectory. Cancer support groups motivate them for self-disclosure, they can express whatever they feel, which may not be possible with a family member and seek help from the individual who also goes through the same. The safe space to detoxify death, expose their vulnerabilities and be themselves while seeking autonomy is created through support groups.
Gulia Cambieri proves after reading the surveys done in the US on 12 September 2024 that social isolation, the objective condition of lacking social ties and loneliness, the subjective condition in which one feels psychologically isolated, are correlated with all kinds of health problems, including mental illness, cardiovascular disease and even premature death

(Cambieri, 2024). The World Health Organisation cautions that the effects of social isolation and loneliness are seen in physical and mental health, quality of life and longevity. Those who lack social connections and eventually undergo loneliness and social isolation are at high risk of developing heart disease, stroke and dementia, besides deteriorating the condition of cancer. The American Psychological Association defines loneliness as emotional distress when patients feel that their inherent needs for intimacy and companionship are not met. They long for companionship and community living, deprived of the external appearance of cancer. Cancer patients often suffer from a lack of intimacy with their spouse, and their marital life is often threatened by the illness. Also, their relationship with others is threatened by the illness, which should be intervened. Not only do the patients need to be catered to, but including the family members in improving their knowledge about the illness, treatment, and side effects of treatment and educating them on managing the issues with patients also helps patients to cope with the intimacy issues and marital issues effectively. (Boccia, 2022).

The energising and revitalising characteristics like empathy, genuine care, humour, exchange of knowledge, acceptance, eradication of stigma and decision-making will create a community living. To alleviate the pain and agony of the cancer patients, this community living must focus on collective well-being rather than individual success. Community living in reality does away with isolation caused by cancer and creates stronger social bonds among cancer patients and supportive groups. This community living enables the mental health of patients, which helps them to reconcile with reality. Soumyalit Bhar and Kalpita Bhar Paul, after their study on urban living and consumerism, state their findings in the following way: Improving mental health requires embracing community-oriented living that challenges the individualised lifestyle promoted by consumer culture. Modern consumerism equates freedom with personal consumption, weakening social bonds that traditionally held communities together. In contrast, community living fosters sustainable alternatives – shared responsibility, collective purpose, and mutual support create an environment that nurtures emotional and psychological well-being (Soumyajit Bhar, 2024).

In community living, patients and support groups share resources and experiences to eliminate isolation and depression. The strengthening of social support networks and the advent of the value of interdependence will emerge in community living. The patients will bring forth empathy, mindfulness, human connection and fulfilment. The patients experience a sense of belonging, purpose and security in community living that is the source of life. Community living becomes the inevitable need of cancer patients (Jennifer Kue, 2022).

RESEARCH METHODOLOGY

Objectives

- To understand the group formed among the cancer patients
- To identify the advantages and disadvantages of the group formed
- To know if Guided imagery helps them to facilitate management of the symptoms

Research Design

It is a qualitative study using observation method. The researcher observed the population without direct involvement to understand their group and how it helps them in their ecological space. Here, the researcher acts as a silent observer. After observations for a month, the researcher started giving them Guided imagery to help them cope with the symptoms. The researcher has acquired training in Guided imagery therapy.

Universe of The Study

The researcher observed patients in the radiotherapy ward in a cancer hospital. The population of the study is 30 patients who were enrolled as inpatients at the time of the study.

Sampling

As the population is low, the researcher used the census method and included everyone present in the ward for the study.

Inclusion and Exclusion Criteria:

The researcher included only patients in the radiotherapy ward who were admitted as inpatients. As the study is about community living, the researcher observed patients who lived as a community irrespective of their religion, caste, education, etc. Patients who underwent radiotherapy alone stayed in the hospital, and so understanding their group dynamics was feasible. Patients undergoing chemotherapy were not staying in the hospital, and patients who underwent surgery stayed in separate rooms; therefore, they were excluded from the study.

Ethical Considerations

The patients were not informed when observations were made, but while giving guided imagery, they were informed about the study and consent was obtained from them. At the beginning of the study, the researcher obtained permission from the hospital and got consent from the patients. As this is mostly observational and does not involve medications, the hospital permitted the study without ethical clearance from the committee.

Observed Characteristics of This Support Group:

Empathy:

The cancer patients in the support groups exchange core empathy with each other. This empathy provides strength to the patients, unlike empathy from relatives and clinical professionals, as the support group itself suffers from all the symptoms of cancer treatments and the illness itself. This attachment offers patients a sense of satisfaction in knowing that there is

someone who can truly understand what they are going through, based on their experience of symptoms, rather than assuming how it will be.

Friendship:
Patients form a community in the hospital through friendships, sharing knowledge they have acquired through experience. They feel safe and happy to witness a healthy prognosis with each other and support one another through the side effects of treatment. Sometimes they even help each other, offering small financial help by buying fruits and tender coconut when one caregiver of a patient goes out, he buys it for a neighbouring friend as well.

Genuine Caring:
All the patients care for each other as they expect nothing in return. They offer genuine support and help each other cope with the exhausting days and severe life-threatening symptoms. Being present during times of distress and accompanying them through this phase shows great companionship, which is what is expected in a support group.

Humour:
The members of cancer groups express their sorrow through different forms of humour. Humour is effectively used as a coping mechanism. The members of the group tend to open up about their symptoms, pain, difficulties, and sufferings in a hysterical way, and all the members, over time, laugh about it and get through it.

Exchange of Knowledge:
These support groups help them expand their knowledge both about patients' rights and about the recent trends and developments in cancer treatments and medical insurance schemes. One patient communicates about her illness and the type of treatment she gets, which has helped her improve. Another may talk about any simple home remedy that offered relief from a specific symptom. This improved the level of confidence among patients to talk to the clinicians. Most of the patients hesitate to ask doubts to professionals, feeling low, but this support group helps them to be confident and courageous enough to ask doubts about their illness to anyone, for that matter.

Acceptance:
Support groups help patients to accept the illness and kindle hope and faith for a better tomorrow. When patients see others suffering from the same illness and showing characteristics of bravery and confidence, they tend to imitate them and try their best to survive the disease. They accept the illness and, with the help of other patients, travel the treatment trajectory with hope and positive feelings to move forward rather than getting stuck in the thought of getting this dreadful illness in the first place.

Eradication of Stigma:
Stigma around cancer is more tormenting than the illness itself. Patients get excluded by their own family members, and get dumped in marriage. The community they belong to scares them, saying cancer causes death. Lack of knowledge is the root cause of all these issues. In rural areas, they still believe that if someone has cancer, they will definitely die, and cancer is contagious. Therefore, patients living in those communities isolate themselves and abstain from participating in any sort of social gatherings. These social practices not only push patients into solitude but also make them feel worthless; they lose their interest in life, and die not mainly because of illness but because of the stigma. Cancer support groups help them to eradicate stigma through extending their knowledge of illness and its treatment. It helps them to relive the lost happiness and exposes them to trustworthy relationships that their family members cannot offer.

Decision Making:
Cancer support groups empower their members to make independent choices and help them take control of their lives. They help patients to become empowered and increase their ability to decide their treatment options and what they want in life.

Challenges Faced Within Support Groups
Patients are from different backgrounds, and each of them experiences pain and associated symptoms on a different level. While support groups may be beneficial in many aspects, it may be frightening to know what they are about to experience by visually experiencing the sufferings of others. Also, the availability of physical space where they can discuss sensitive conversations is not sufficiently available in most of the hospital settings (Hasson F, 2021). Patients may suffer from confronting their peers' death from the illness, and that adds stress to their emotional state, apart from their individual emotional distress. They may lack confidence and hope to recover. Hearing about the sufferings of others from the same illness may discourage them from opting for future treatments, fearing they would end up the same as others. Compared to them, other peer members may lead to isolation and survival guilt. Sharing of knowledge may harm the peer members; some may not be ready to receive too much information, some may not understand the information shared, and some may have limited resources to provide from their own experience. Divergent information confuses patients and may lead to depression. The different dynamics of the group also cause tension among members; the group may force some to show emotional openness when they are not ready, members may feel uncomfortable when someone boasts about their success, and when family members are included in the group, patients may not be open about their emotional state. Sustaining the longevity of the group is also considered a major challenge (Martina Jablotschkin, 2022)

Deliverance of Guided Imagery As a Relaxation Technique

Guided imagery given to cancer patients helps them recover and heal from the treatment. It enables the patients to create positive mental images that facilitate peace, hope, courage, and faith, and the patient may experience tranquillity in the process. Through guided imagery, their stress level is reduced, a sense of control over life is achieved, and comfort during the administration of the treatment, like radiotherapy, is obtained. Knowledge of cancer and cancer treatment, and its unanswered questions, is addressed through guided imagery, and patients become self-aware. The harmful beliefs about cancer treatment are replaced with what happens in the treatment process, and guided imagery strengthens the patients to withstand the treatment process and supports them in effective healing. Although guided imagery is helpful, it should always be used in conjunction with the medical treatment that suits the patient's tumour. Therefore, guided imagery should be used along with chemotherapy, radiotherapy, or surgery for the effective recovery of patients from cancer. The usage of this technique in oncology was first accelerated because of the studies of oncologist Carson Simonton, who did a series of studies on how psychotherapeutic interventions decreased the psychological disorders of cancer patients. One important technique among them was guided imagery. Clinicians at different hospitals used guided imagery to check its influence on bodily aches, and pain associated with cancer treatments, and the psychological issues like anxiety and depression associated with the incidence of the illness, and it was found that guided imagery helped in all aspects and improved the quality of life of cancer patients suffering from all these symptoms. The patients benefitted from this and showed positive mental health and emotions, control over their emotions and pain, and improved self-awareness (Ozu, 2010).

Implementation of Guided Imagery

- The instructor will create a relaxing environment by playing calm music in the background using headphones so that the external hospital chaos can be avoided.
- A cloth will be placed above their eyes to avoid distraction.
- Patients are asked to lie in their comfortable position.
- The instructor will guide them to focus on their breath, their inhalation, and exhalation.
- Later, they will be guided to imagine a mental image of a relaxing background, be it a beach or a forest. Analysis of any trauma associated with the above-mentioned scenes will be inquired while taking a case history and will be made note of it.
- The instructor will help them focus their attention on body parts that feel sore or painful, and she will help them relax those particular parts.
- The instructor will picture radiation beams as sunlight, which eradicates and kills the germs with warmth. Here, the germs are related to the cancer cells.
- The instructor asks the patients to experience the healing process of the body when the radiation rays are on them.
- Positive affirmations of their body and health will be provided, like I feel warm, My body is healing, I will cooperate with all the treatments, I can endure this, I feel hopeful, I am worthy, I will recover soon etc.
- The technique will end with breathing exercises.

Comments (Verbatim) From The Patients After Implementing Guided Imagery

- “Do not give up your heart while having to suffer in your body and agony in your heart. After listening to this, I felt courage and eventually had a sense of boldness from head to foot”.
- “It was so pleasing and normal after listening to this recording. We do not need to think of our problems again. As snow and rain fleet our problem will go away. Like a bird flying in the rain, we should do away with suffering and agony and live with courage”.
- “For them, it was very cool, calm, refreshing and joyful” Their expression proves that they are reconciled with the reality of having cancer. Some patients said, “It was so amusing to listen. I became inexplicable”.
- “I was at peace. It was very charming and hassle-free”.
- The husband of the patient responded to the researcher, “Throughout the night, she did not sleep. But after hearing this, she had a sound sleep throughout the night.
- It was so good. It was so tranquil. My worries have gone away. It was calm and well done.
- While listening to this, I felt serenity in my heart. I got rid of my worries.
- I was so relaxed, after hearing this, the encumbrance of my heart was lightened.
- Without any distractions, we must concentrate on breathing for relaxation. Focusing attention on hands and legs relieves pain in them. We should not think about anything.

Guided imagery helped patients to move free from exclusiveness, hesitation, ignorance, hatred, despair, loneliness, negativity towards inclusiveness, freedom, knowledge, love, hope, community living, positivity

CONCLUSION

Diagnosing cancer is a stressful or painful event after which patients withdraw from social interactions. Social isolation is minimal contact with other people and limited or no involvement in community life. But both social isolation and loneliness cause cancer suffering and mortality. From this field study, I understand that strong social connections, supportive groups or communities, mutual help and sharing, suggestions and community living are very pivotal to cancer patients. The supportive groups and patients find their meaning and purpose in life, the satisfaction of living on this earth and the fulfilment of life in community, collective effort and action and in friendship and living together. Community

living in Brazil has motivated the inhabitants to reconnect by sharing responsibilities and cultivating a sense of belongingness. The social worker ought to facilitate community living for the patients.
Cancer support groups should be mandatory in all oncology treatment facilities, as they benefit patients, especially those receiving palliative care. But these groups should be formed with professional help, like social workers who are professionally trained to deal with the intense emotions of these patients with controlled emotional involvement. As a conclusion, support groups help patients to rely on themselves, improve their relationships, and offer a strong friendship that fosters core empathy that none could experience. Support groups help them to be empowered, and their vulnerability and loneliness are lost. Cancer patients find solace in these groups and cope with the help of fellow patients.

Author contribution:
The entire article is articulated and drafted by the corresponding author and her team.

Acknowledgement:
I want to thank all the patients and support groups and their caregivers who helped the author and team to know about their way of living with cancer in a palliative care centre.

Declaration of patient consent:
Patient's ID is not mentioned or compromised, and so patients' consent is not required.

Conflict of interest:
There are no conflicts of interest

Financial Support: Nil

REFERENCES
1. Andrew J. Winzberg, C. C. (2003). Evaluation of an Internet Support Groups for Women with Primary Breast Cancer. American Cancer Society, 97, 1164-73. doi:10.1002/cncr.11174
2. Boccia, M. L. (2022). Social relationships and relational pan in brain tumor patients and their partners. Frontiers n Pain Research, 3. doi:10.3389/fpain.2022.979758
3. Cambieri, G. (2024). Loneliness is hurting our health, but these policies could help. Harvard: Harvard T.H. CHAN. Retrieved from https://hsph.harvard.edu/news/loneliness-is-hurtng-our-health-but-these-policies-could-help/
4. Fang-Yu-Chou, F. L.-L. (2016). The effectiveness of support groups in Asian breast cancer patients: An integrative review. Asia-Pacific journal of Oncology/Nursing, 3(2), 157-169. doi:https://doi.org/10.4103/2347-5625.162826
5. Hasson F, J. J.-W. (2021, jan). Challenges for palliative care day services: a focus group study. BMC Palliative care, 20(1). doi:10.1186/s12904-020-00699-7
6. Jane Ussher, L. K. (2006). What do cancer support groups provide which other supportive relationships do not? the experience of peer groups for people with cancer. Social science and Medicine, 62, 2565-2576. doi: doi:10.1016/j.socscimed.2005.10.034
7. Jane Ussher, L. K. (2006). What does cancer support groups provide which other supportive relationship do not? The experience of peer support groups for people with cancer. Social Science and Medicine., 2565-2576.
8. Jennifer Kue, K. K. (2022, August 30). ONS|VOICE. Retrieved from Social and Community context Matter in Cancer Care: http://www.ons.org/publicatons-research/voice/news-views/08-2022/social-and-community-context-matter-cancer-care
9. Martina Jablotschkin, L. B. (2022, september 14). Benefits and challenges of cancer peer support groups: A systematic review of qualitative studies. European Journal of Cancer Care, 31(6). doi:https://doi.org/10.1111/ecc.13700
10. Mette Trep Hoybye, C. J.-T. (2005, July 15). Online Interaction. Effects of Story Telling in an Internet Beast Cncer Support Group. Psycho-Oncology, 211-220. doi:10.1002/pon.837
11. Ozu, O. (2010, November 29). Guided magery as a psychotherpeutic mind-body intervention in health psychology: A brief review of efficacy research. Europe's Journal of Psychology, 6(4), 227-237. doi: https://doi.org/10.5964/ejop.v6i4.232
12. Rie Tamagawa, Y. L.-D. (2014, August 06). Deconstructing therapeutic mechanisms in cancer support groups: do we express more emotion when we tell stories or talk directly to each other? Journal of Behavioural Medicine. doi:10.1007/s10865-014-9589-y
13. Soumyajit Bhar, K. B. (2024, October 10). Mental health in India's material world. The Hindu (Tiruchirapalli), p. 08.