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Families of Terminally Ill Cancer Patients

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Northwestern College Social Work Department

Family Systems: Theory and Practice

Dr. Valerie Stokes

December 11, 2023

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Abstract

Cancer is an illness that does not only impact the patient, but also the people around them. It can be especially difficult for families who are affected as it impacts the lifestyles of everyone. Approximately 1.9 million new cancer cases are expected each year to occur in the United States, so this is an issue that will continue to be prevalent. (American Cancer Society, 2022). Research has shown that there are many effective methods that can be used to help families. This includes methods such as family-based dignity intervention (FBDI), meditation, and open communication strategies. It is important for social workers to understand these concepts and their effectiveness because it allows them to provide as much assistance and comfort as possible.

Families of Terminally Ill Cancer Patients Literature Review

Statistics about the population

Cancer impacts families all over the globe. When looking at the population of families who have a member in the family who is suffering from terminal cancer, it is clear that cancer does not discriminate. These families are all around the world, and their stories vary from the severity of cancer to the home life they interact in. However, in this literature review, the focus will be on families within the United States. According to the American Cancer Society, in 2022, "a total of 1.9 million new cancer cases and 609,360 deaths from cancer are expected to occur in the US, which is about 1,670 deaths a day." (American Cancer Society, 2022). All these deaths have an enormous impact on families. When looking at the statistics regarding the increase or decrease in deaths regarding cancer, there is a definite drop in these numbers. Between 1991 and 2019, there were roughly 3.8 million fewer deaths due to fatal cancer diagnoses. While the number of deaths from cancer is decreasing, it is still a prevalent issue. The National Cancer Institute also makes the mortality rate of cancer patients known from the years between 2013-2017. "The cancer death rate is 158.3 per 100,000 men and women per year (based on 2013– 2017 deaths)" (National Cancer Institute, 2020). Terminal cancer affects many people around the world.

Characteristics and common issues

According to Zaider and Kissane, "in the advanced stages of illness, families manage multiple caregiving demands while facing the emotional task of preparing for the loss of their loved one" (Zaider & Kissane, 2009). These families are dealing with the idea of loss with specific family members, and this loss can be extremely heartbreaking and difficult for the majority of these family systems. Palliative care often comes into play when the concept of

terminal patients is brought to the spotlight, and most times, the support and care of a friend or family member is necessary to the well-being of the patient. Some common issues that are reported are in relation to the dysfunction that families endure during the diagnosis of a family member with terminal cancer. Kuhne et al., write that when "studying cancer families, a relation between family functioning and psychosocial distress is frequently reported; however, there seems to be discord about its direction, as well as about potential mediator and moderator variables" (Kuhne et al., 2013). People who are affected by terminal cancer often worry about how their family dynamics will change and how each member will feel the effect of the loss.

Risk factors

There are many significant risk factors to populations who have immediate family members suffering with terminal cancer. Authors Alexander, O-Connor, and Halket talk about the psychosocial effects of parental cancer with patients' dependent children. Some children are vulnerable to long-term problems, such as post-traumatic stress symptoms. It may even lead to self-harm and suicidal ideation. In their study, they worked with twelve children aged 5 to 17 years who are living with a parent with cancer. The childrens' parents were at different stages of cancer at the time of the interview, including stage II, stage III, stage IV, and in remission or deceased. They found that children experience tremendous levels of worry and distress when a parent is diagnosed with cancer. They feel disconnected from their usual support systems and feel limited with who they can reach out to. Patterns showed that because the children witness the physical and cognitive changes associated with cancer, they experienced the worries and distress more severely. They also had a tendency to worry about their own likelihood of being diagnosed with cancer. Long-term consequences included post-traumatic stress disorder, anxiety and depression, obesity, and alcohol and substance abuse (Alexander et al., 2023).

The study by Thomas et al. researched the development of prolonged grief in family carers of cancer patients in palliative care. They confirmed "previous findings that caregivers of patients receiving palliative care have a high prevalence of psychological distress during bereavement" (Thomas et al., 2014). This psychological stress consists of grief that continues intensely beyond the time frame that is expected and that is significantly disruptive to a person's life. They also noted that female carers have significantly greater psychological distress than male carers. They said that "generally, the loss of a close relationship...is associated with greater risks to health" (Thomas et al., 2014). For spouses who act as carers for patients with terminal cancer, there is a high risk of experiencing symptoms intensely and for a long period of time, as well as increased risks to physical health.

Major concerns or problems for this population

The major problem for this population is dysfunction and support within the family system. According to Chua et al., "caregivers' burdens can be increased due to the patients' unmet needs and unresolved problems. Additionally, the caregivers' unmet needs may adversely affect their own well-being and the patients' health outcomes" (Chua et al., 2020). The idea that these patients feel like a "burden" is a common occurrence within families who are caring for a palliative individual. On the flip side, the caregiver may feel like their own needs are not met due to the feeling that the care for their terminally ill family member is more important than their own well-being. This dysfunction between burden and personal well-being can create dissonance in a family system, and if these steps are not taken seriously, it can lead to the destruction of a family circle.

Another major problem is that "the long-term process of providing care is physically and psychologically demanding, especially when caring for patients with advanced cancer. The

burden of caregiving may manifest in symptoms of sleep difficulties, depression, anxiety, tension, panic, or behaviors that may jeopardize the FC's health" (Chua et al., 2020). This long process is exhausting not only for the patient, but also for their personal caregivers. The emotional well-being of both individuals is so integral to the system of a family circle.

Engagement

For children who have a parent with terminal cancer, it is important for them to be able to talk to someone about their parent's diagnosis. In the study The Psychosocial Effect of Parental Cancer: Qualitative Interviews with Patients' Dependent Children, children "preferred to talk and be supported by their parents, [but] parents were often unavailable and they were limited regarding who they could seek out" (Alexander et al, 2023). It is important for the social worker or therapist to be a safe space to explain this situation to children. A social worker interacting with children who have a parent with cancer should make sure to be knowledgeable, yet sensitive. While they cannot replace a parent's comfort, they should make themselves available for what the child needs. The study says that "parents are often overwhelmed by their own experiences and challenges associated with the cancer diagnosis, making their physical and mental availability to children challenging" (Alexander et al., 2023). It says that all children require some level of support to help them through the diagnosis. It is because of this that when interacting with children who have parents with terminal cancer, a therapist should make sure to facilitate discussion to help them articulate their thoughts, and the social worker should make sure they are knowledgeable yet ready to listen.

In general, spouses of patients with cancer often take on the caretaker role. These roles often consist of caring for the patient's "hygiene, medical support, emotional support, financial and legal tasks, household duties, patient advocacy, and consultation with health professionals"

(Thomas et al., 2014). Because the spouse has to take on all of these duties, it is important for a social worker to utilize interventions to deal with their stress. In addition to the distress of discovering that their loved one has cancer, they also have to take on many other responsibilities that aren't typical household tasks. Many of these spouses also have children, so they have to balance taking care of them as well. The social worker should be aware of this when engaging with this population. It could be useful for them to incorporate ways to try to balance all the new tasks they have.

Terminology

There are a few important terms and phrases that are important to understand when working with families of patients with terminal cancer. Many spouses take on the role of a carer. Thomas et al. describes family carers within the context of palliative care. They say that this is as "a relative, friend, or partner who has a significant relationship and provides assistance to a person with a life-threatening, incurable illness" (Thomas et al., 2014). It is important for a social worker to know this because their clients may take on this role. Therefore, the social worker needs to understand what kind of duties they have in order to support their clients in the best way they can. It is also important to understand one of the most common symptoms that come with having a family member diagnosed with cancer. This is known as prolonged grief disorder. This is defined as "grief that continues in intensity beyond a time frame in which some form of adjustment is expected and to an extent that it is significantly disruptive to a person's life" (Thomas et al., 2014). It is beneficial to know this disorder because it is common, and normal, for a family member to grieve the diagnosis or loss. However, intervention needs to occur when it is significantly longer and more disruptive in a person's life than normal grief.

Another important term for a social worker to understand is palliative care. Palliative care is "specialized medical care designed to improve quality of life for you and your family" (Asanga, 2023). Regarding terminal cancer, it mainly focuses on alleviating symptoms and making sure the patient is comfortable. It also helps with support for family members. It is important for a social worker to know what this means as they will likely be working with medical providers to ensure palliative care for the patient and the patient's family. Finally, it is important for social workers to understand the definition of terminal cancer. In the article *What is terminal cancer?*, Asanga says that terminal cancer is "the final stage of cancer, which is why it also described as 'end-stage cancer.' The disease continues to grow and spread advanced cancer from which recovery is not expected" (Asanga, 2023). This is important for a social worker to understand because this knowledge allows them to understand the point of the living process that the terminally ill patient is currently going through.

Framework

One of the most important frameworks for family therapy is the strengths perspective. The strengths perspective is used often in social work, and it can be very beneficial when working with families with a relative diagnosed with cancer. Gray's article about the strengths perspective model talks about some of the characteristics of the model. It says that people grow when the social worker affirms and supports their ability to grow. The social worker must believe the client, explore what the client wants, use the client's words, make assessments together, reach mutual agreement, and avoid blaming (Gray, 2011). Gray adds that the strengths perspective focuses on nurturing. This is important for families of patients with terminal cancer because it shows sensitivity and empathy. Instead of pushing family members out of their comfort zone and past their safe boundaries, it focuses on their current skills. It also builds on

what they have instead of making them start new. This can help alleviate stress that they are going through with the news of the diagnosis.

The strengths perspective also has a humanistic foundation. Gray states that this means it focuses on "mutuality and connection with each other, as well as respect for and affirmation of human dignity" (Gray, 2011). The social worker and the client develop a relationship that consists of trust, creating a safe space to talk about whatever is necessary. Whether the client is the spouse of someone with terminal cancer or the child of one, each person needs a space to be able to vent, cry, and talk about their concerns. The social worker makes sure to not minimize or ignore problems but ask questions and empower the client to recognize and realize their potential (Gray, 2011). The strengths perspective is important for these human relationships and the support gained from them.

The strengths perspective model is the most important to keep in mind because of its emphasis on relationships, especially the relationship between the therapist and the client. The strengths perspective offers empathy and listening, as well as motivation and flexibility. The therapist and the client learn to build trust while also encouraging the client to grow in a healthy way. This model is good for clients of all ages and in various walks of life who have a family member diagnosed with terminal cancer.

Research-Informed Practice: Article Summaries

Citation:

Valero-Cantero, I., Casals, C., Espinar-Toledo, M., Barón-López, F. J., Nuria García-Agua Soler, & María Ángeles Vázquez-Sánchez. (2023). Effects of Music on the Quality of Life of Family Caregivers of Terminal Cancer Patients: A Randomised Controlled Trial. Healthcare, 11(14), 1985. https://doi.org/10.3390/healthcare11141985 Introduction:

Auditory signals are an important aspect of human sensory systems, and music has a capacity capable of inspiring emotions. The goal of this study was to explore the potential benefits of listening to self-chosen music on the quality of life of family caregivers of cancer patients who are receiving palliative home care. The researchers hypothesized that the intervention group would achieve a greater improvement in quality of life than the control group after the seven-day intervention.

Procedures or Description:

This was a double-blind study in which the intervention group received a music medicine intervention for seven consecutive days while the control group received conventional treatment for seven consecutive days. All 82 participants were eighteen or older and were family caregivers for cancer patients in palliative patients; they also all received conventional treatment in the same conditions before the intervention. The intervention consisted of a thirty-minute music session received daily for seven days and the caregiver was told not to perform any other activity during that session.

Findings:

The study showed significant improvement in the quality of life reported and increased satisfaction with health care for those who had the intervention. They saw improved physical well-being and social concerns, but no significant differences for the spiritual scale. There was also no significant difference in psychological well-being, though the intervention group reported improved psychological well-being.

Conclusions:

The results provide evidence to support the use of musical interventions in home-based palliative care for family caregivers of terminally ill patients as the intervention was proven to be highly effective in improving quality of life and satisfaction.

Citation:

Zhou, J., Chen, X., Wang, Z., & Li, Q. (2023). Couple-Based Communication Interventions for Cancer Patient–Spousal Caregiver Dyads' Psychosocial Adaptation to Cancer: A Systematic Review. *Healthcare*, 11(2), 236. https://doi.org/10.3390/healthcare11020236

Introduction:

It is essential to have effective communication between couples when one has been diagnosed with cancer in order to improve their psychosocial adaption to the disease. This is because open communication could promote better coping through discussion of problem solving, impact the adjustment to cancer through discussion of feelings and other interactive coping mechanisms, and help both partners adjust to a lifestyle that consists of cancer. The goal of this review is to summarize couple-based communication interventions in the context of cancer, explore these interventions' feasibility and acceptability, review their impact on the relationship and functioning, and identify future research directions.

Procedures or Description:

The researchers performed a systematic search through six English databases and two databases from China. They targeted articles with research about a couple with one who has a diagnosis of cancer, interventions focused on couple communication, articles that measured relationship and functioning, and that were published in peer-reviewed journals in English or Chinese. They used

the Effective Public Health Practice Project (EPHPP) to examine bias and assess the quality of the articles.

Findings:

14 studies were included in their review from the 979 total that they found according to the inclusion and exclusion criteria. They found that the types and stages of cancer impacted the specific communication needs and topics such as cancer-related experience, thoughts, feelings, and relationship issues. It is also necessary to emphasize the importance of varied topics including cancer-related emotional disclosure, healthy issues, and relationship topics. Finally, self-disclosure and partner responsiveness was important for improving the sense of feeling understood, validated, and cared for.

Conclusions:

The researcher's major outcome of the study is that couple-based communication intervention improved couples' relationships and individual functioning and improved the psychosocial adaptation to cancer.

Citation:

Tahereh, N. G., Seyedfatemi, N., Bolhari, J., Kamyari, N., & Rezaei, M. (2023). Effects of family-based dignity intervention and expressive writing on anticipatory grief in family caregivers of patients with cancer: a randomized controlled trial. *BMC Psychiatry*, 23, 1 11. https://doi.org/10.1186/s12888-023-04715-x

Introduction:

Anticipatory grief is a typical psychological problem among family caregivers of cancer patients that occur when the caregiver thinks about the threat of death and separation. It can affect the stress of the caregiver and may affect cancer patients and their treatment process due to decline caregiving quality. The study was conducted to assess the effects of family-based dignity intervention and expressive writing on anticipatory grief of caregivers of cancer patients.

Procedures or Description:

The researchers included 200 caregivers who were the first-degree relatives of cancer patients and who had the most responsibility for the caregiving of them, those who cared for patients who were dying or critically ill, and those 18 years old or older. These caregivers were randomly assigned to one of four intervention groups: family-based dignity intervention, expressive writing intervention, combined family-based dignity intervention and expressive writing, and control group. Anticipatory grief was evaluated using the 13-item anticipatory grief scale before the session and 1 and 2 weeks after the session.

Findings:

A total of 188 caregivers completed the study. They found a significant effect of family-based dignity intervention, compared with the control group, using the anticipated grief scale. They found no significant effect on the anticipated grief scale regarding expressive writing and combined intervention.

Conclusions:

Family-based dignity intervention improves anticipatory grief and its subscales in caregivers of dying cancer patients when presented by an experienced nurse.

Citation:

Ahmad, M. M., & Al-Daken, L. (2022). Clinical Trial on Mindfulness with Family Caregivers for Patients with Cancer. *Journal of Cancer Education*, *37*(2), 304-310.

https://doi.org/10.1007/s13187-020-01812-3

Introduction:

Shifting care toward home-based services addresses the importance of looking at the needs, well-being, and burdens for family caregivers. The concept of mindfulness has been recognized as a safe practice for improving psychological state for the past three decades. This study's purpose is to examine the effectiveness of brief mindfulness-based interventions and educational interventions for family caregivers of patients with cancer.

Procedures or Description:

The researchers recruited both patients and caregivers in waiting areas of clinics in selected hospitals as well as being invited individually by the PI or assigned nurse. The MBI intervention was a five-week mindfulness-based training where all caregivers attended 150 minutes of face-to face sessions in the first and second week and a 20-minute weekly follow-up phone call in the remaining three weeks, as well as practice at home to guide them through their mindfulness exercises. They also were given an educational booklet addressing the needs for information and training of caregivers for patients at the end of life, including information about pain, mobility, personal care, and more. The researchers measured self-efficacy and the levels of burden for family caregivers.

Findings:

The researchers found that the levels of self-efficacy and burden both improved significantly among family caregivers after the implementation of brief mindfulness-based interventions. They found that while the levels of burden for family caregivers decreased after they received the educational intervention (the pamphlet), it was not statistically significant. The educational intervention was statistically significant in improving the levels of self-efficacy for family caregivers.

Conclusions:

While further research is still needed, this study found that brief MBIs hold optimistic results as an intervention to enhance self-efficacy and reduce burden in family caregivers while educational interventions were helpful in aspects of self-efficacy, but not reducing burden.

Citation:

Milton, K., Poole, K., Cross, A., Gasson, S., Gokal, K., Lyons, K., Pulsford, R., & Jones, A. (2022). 'People don't get cancer, families do': Co-development of a social physical activity intervention for people recently affected by a cancer diagnosis. European Journal of Cancer Care, 31(3), e13573. https://doi.org/10.1111/ecc.13573

Introduction:

Physical activity improves cancer-specific mortality and risk of cancer recurrence, as well as optimizing the effects of cancer treatment and reducing side effects. Research has shown that having a strong social network is a significant driver of physical activity in patients with cancer. When people perceive cancer as a shared experience, they experience better physical, mental, and relational outcomes.

Procedures or Description:

Semi-structured interviews were conducted by telephone or face to face and covered the facilitators and barriers to physical activity among cancer patients and their friends and family. They also talked about what they would want to see in a physical activity intervention and how a social intervention to promote physical activity for patients and their support systems could be embedded into cancer care.

Findings:

37 people were interviewed, and it was agreed by all of them that the impact of a cancer diagnosis is a shared experience. Participants felt that a social intervention would be likely to result in successful behavioral change for both the client and the client's families. The cancer patient would feel increased motivation, and the families may feel helpless and not know how to best show support. The researchers did find mixed views on the appropriate time to introduce physical activity as some people believed they should encourage it at the point of diagnosis while others felt that adjustment time was necessary.

Conclusions:

This intervention is a flexible treatment designed to support cancer patients and their families to be active through treatment and beyond, benefiting all parties' physical and mental health.

Citation:

Seyedfatemi, N., Ghezeljeh, T.N., Bolhari, J. *et al.* Effects of family-based dignity intervention and expressive writing on anticipatory grief of family caregivers of patients with cancer:

a study protocol for a four-arm randomized controlled trial and a qualitative process evaluation. *Trials* **22**, 751 (2021). https://doi.org/10.1186/s13063-021-05718-3

Introduction:

This is a study that looks at the effects of family-based dignity interventions as well as expressive writing in regards to anticipatory grief for family members who give care to patients with cancer. Anticipatory grief is one of the main problems that family caregivers of patients with cancer face, and this study allows us to take a look at how to better handle these situations.

Procedures or Description:

There is one quantitative and qualitative method that are used to aid in this mixed-methods study. The participants involved will go through a four-armed randomized controlled trial, and according to the article, the focus is on four things: "(1) combined family-based dignity intervention and expressive writing, (2) family-based dignity intervention alone, (3) expressive writing alone, and (4) routine care on anticipatory grief of family caregivers of dying cancer patients" (2021). Each participant will be rated on an anticipatory grief scale and ranked according to their score.

Findings:

This study is still currently in the process of going through its methods and participants.

Conclusions:

As the study progresses, there are promising results that researchers are already beginning to see.

Citation:

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A novel Family Dignity Intervention (FDI) for enhancing and informing holistic palliative care

in Asia: study protocol for a randomized controlled trial. (2017). NTU Singapore.

https://doi.org/10.1186/s13063-017-2325-5

Introduction:

The defining moment in palliative care is psychological and spiritual support, and that is what

this study focuses on. The idea of holistic care is the main focus of this study in Asia, and it

seeks to understand how to better support family members of cancer patients.

Methods/Procedures:

This study uses an open label randomized controlled trial design. The sample is comprised of

126 Asian families in Singapore, and patients needs to be over the age of 60 as well as in long-

term care for their cancer. These families are randomly allocated to one of two groups: (1) an

intervention group (FDI offered in addition to standard psychological care) and (2) a control

group (standard psychological care).

Findings:

This study is still currently in progress; however, the data looks promising in supporting the

theory.

Conclusions:

This article/study is expected to make a difference in Asia and in families with family members

who are under palliative care for their cancer. It will serve as the base for much future research

on effective methods for treatment.

Citation:

Chunfeng Wang, Jingyi Chen, Ying Wang, Wenkui Xu, Mengting Xie, Yong Wu, Rong Hu.

Effects of family participatory dignity therapy on the psychological well-being and family function of patients with haematologic malignancies and their family caregivers:

A randomised controlled trial, International Journal of Nursing Studies, Volume 118, 2021, 103922, ISSN 0020-7489, https://doi.org/10.1016/j.ijnurstu.2021.103922.

Introduction:

Research has shown that strong family ties seem to lesson cancer patients' difficult experiences. It also has been beneficial for the patients' family members who are also going through these life and health crises. This study aimed to confirm the effectiveness of family participatory dignity therapy in improving the psychological well-being, family cohesion, and adaptability of patients with cancer and their caregivers.

Procedures or Description:

The researchers conducted a single-blinded randomized control file with 68 pairs consisting of a patient and their family member. Each pair was interviewed two or three times, and their hope, spiritual well-being, family cohesion and adaptability was evaluated for the patients. Their family members were evaluated for depression, anxiety, and family cohesion and adaptability.

Findings:

The family participatory dignity therapy showed a positive effect regarding patients' hope, spiritual well-being, and family cohesion and adaptability. It offered patients and families an opportunity to discuss important issues and disclose true feelings. It allowed a space for a sincere conversation. It also alleviated family caregivers' anxiety, depression, and enhanced their family cohesion and adaptability.

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Conclusions:

Family participatory dignity therapy was effective for both patients and families in providing

open and guided conversation without fear of repercussions.

Family Treatment Curriculum

The purpose of family therapy when one member of the family has cancer involves many

different strategies, but open communication is arguably one of the most important. Family-

based dignity intervention is a strategy that focuses on open communication and was adapted

throughout this specific family group to involve all members in the household.

Family Treatment Plan

This form will be reviewed again in no more than two months, and progress toward goals will be

noted. Changes in interventions or goals should be noted immediately.

Identified Clients: Jim (40), Ann (39), Blaine (13), Gwen (11)

Clinic Record: N/A

Number Insurance: N/A

Diagnosis: N/A

Summary of Patients' Concerns: Ann has

been diagnosed with Stage IV breast cancer and

Jim has found himself as the primary caretaker

while she is receiving treatment. Blaine and

Gwen have been fighting constantly, causing

more stress on both parents.

Identified Patient Strengths and Resources (to be added to throughout therapy):

Strong and unwavering values/beliefs, no parental arguments in front of the children, stable finances, close proximity and relationship with both Jim and Ann's parents

Interview Progress Narrative

Long-Term Goals:

Jim hopes to find a balance in which he can give Ann the care that she needs while also providing for the family. Ann wants to be able to communicate her needs to Jim. Both parents would like Blaine and Gwen to get along better.

Problem/Concern #1: Jim is struggling with taking care of Ann and meeting all of her needs.		
Objective	Intervention	Progress Towards Goal
Foster open communication between Ann and Jim so that eah can properly express what they need from one another. Help Jim to understand his own feelings about the situation and be able to healthily express them. Target Date: Completion Date:	Expressive writing to discover his own feelings. He will then share his feelings with Ann with the help of a therapist. Mindfulness exercises for five minutes a day to allow Jim some time to himself and to get ready for the day ahead. Positive affirmations to help Jim to believe in himself and his capabilities.	
Problem/Concern #2: Blaine and Gwen are not getting along.		

Discover how the two	Creating a painting that	
children feel about each other	depicts what their family	
and what their family looks	looks like to them.	
like.		
	Blind-folded obstacle course	
Create situations in which the	to initiate bonding between	
children will bond over an	the two.	
activity while also	the two.	
establishing trust.	Colored condice activity	
_	Colored candies activity – allows them to understand	
Target Date:		
Completion Date:	one another better.	
Completion Date:		
Problem/Concern #3: Ann is	experiencing distress and loss of	hope as she copes with her
diagnosis.		
Help Ann to see that she is	Mindfulness exercises to	
not defined by her diagnosis.	allow her to focus on where	
	she is at rather than worry	
Instill the belief that Ann is	about the future.	
strong and capable, as well as		
believing that her family	Gratitude exercise – come up	
loves and supports her.	with things Ann is thankful	
T. A.D.A	for starting with each letter of	
Target Date:	the alphabet, especially when	
Completion Date:	it is difficult to be thankful	
1	about anything.	
	about anything.	
	Positive affirmations – repeat	
	these words every morning	
	until they are believed.	
	until they are believed.	
Therapist Signature:		Date:
1 0		
Patient signatures (age 18 or old	ler):	
- · · · ·		
		Date:

I	Date:

Theoretical Orientation

Family-based dignity intervention is an intervention intended to help families who are not strong in their expressions of intimacy and emotions. It helps to facilitate open dialogue between cancer patients and their family caregivers. It aspires to help strengthen family compassion and connectedness by creating a platform for achieving reconciliation, establishing family bonds, and expressing appreciation (Hau Yan Ho et al., 2017). Family-based dignity interventions typically consist of at least four sessions. In the initial session, a trained professional asks the caregiver of a cancer patient a list of twelve questions. These include:

- 1. Tell me a little about your life history with your loved one; what are some of the most important and memorable times you had together? When did you feel most alive with your loved one?
- 2. How has your relationship with your loved one influenced your life?
- 3. What are some things you want your loved one to know about you, or to remember about you?
- 4. What do you think are your loved one's most important and meaningful accomplishments in life (family, career, community)?
- 5. What do you appreciate most about your loved one?
- 6. What do you think your loved one is most proud of you for, or appreciates about you?
- 7. Are there particular things that you want to thank your loved one for?
- 8. Are there particular things that you like to ask forgiveness for, or offer forgiveness for?

- 9. What teachings, advice, or words of guidance have you received from your loved one, and would like to pass on to other family members?
- 10. What are your hopes and dreams for future for your loved one, yourself, and your family?
- 11. In creating this permanent record, are there other things that you would like to include?
- 12. Before the session ends, are there things that you would like to take time to say again?

The therapist makes sure to record video and audio for the answers to each of these questions. As they ask the questions, they help to "structure and organize their thoughts, connect sequences of events, facilitate disclosure of cherished memories, and encourage the expression of appreciation and reconciliation" (Ghezeljeh et al., 2023). Then, the professional creates a coherent narrative using a formatted editing process. Finally, the therapist and the caregiver review the video and transcript to convey the message that is intended to be given.

Because this therapy is being adapted to be used within a family therapy session, a few more techniques were included, which can be seen below. Instead of recording a video, the therapist instead led the caregiving client through the questions with their spouse in the audience. The therapist makes sure to emphasize that the spouse, who has cancer, should remain completely silent while the other person speaks, without giving any reaction or interruptions. Finally, the two clients switched roles. The caregiver takes a turn to listen while his spouse with cancer answers the questions. This therapy is useful because it allows for complete communication with one another about topics that are otherwise difficult to discuss.

Goals and Outcomes

The overarching goal of this curriculum was to create an environment and equip the clients with the tools necessary for open communication and clarity. This was achieved through goals such as assessing initial family dynamics, enabling the expression of feelings about the

cancer diagnosis from every family member, building trust and honesty, and giving strategies for future growth beyond the therapeutic relationship. These goals allow for the family to foster an environment in which every member feels free to express their feelings and needs through the stressful situation of a cancer diagnosis.

Techniques and Methods

There were many techniques that the social workers utilized throughout therapy that were effective in treating a family who has a member with terminal cancer. The therapists also adapted Ghezeljeh et al.'s version of FBDI, or family-based dignity intervention. This was the intervention that the therapists chose to focus on because of its values. FBDI values open communication, which is very helpful when dealing with a situation as serious as terminal cancer. All members of the family system may feel as though they have to be extremely sensitive with one another. They may feel afraid to express what they need from others. This adaptation of FBDI allowed for both parents in the family system to effectively communicate their love for one another, as well as other things that they want to express before they cannot due to cancer. While FBDI happened with the two parents, the children were in another room creating a painting that expressed their feelings about what their family looks like, as well as how they feel about the cancer diagnosis. Open communication as the focus of FBDI inspired this activity for the children because they are not able to express their feelings with words as their parents are.

Expressive writing was another technique that was important to implement. In this strategy, the members of the family were free to write anything and everything regarding the cancer diagnosis. They were informed that their answers would not be shared, so they were encouraged to be completely honest and raw. They also were given exactly fifteen minutes to write nonstop. This was a useful strategy because it forced the clients to come to terms with their

own feelings. They were able to be vulnerable with themselves. This technique relates to the open communication focus of FBDI because it allows for the organization of thoughts, which then can be expressed more easily when the client is ready. The final technique was mindfulness. This was chosen because it is a strategy that allows the user to clear their mind, which is especially helpful when people are constantly in a stressful situation. It was not as related to the focus of open communication that FBDI has, but it is still extremely useful in every person, not just people who are going through a stressful situation. The strategy of mindfulness allows one to be fully present without worry or distraction.

Family Dynamics

Within this family system, there are three concepts that can inhibit the growth of the family: stress, anxiety, and guilt. The social workers had to be sure to address all of these areas in their curriculum to promote the wellbeing of the family. Stress and anxiety occur in each family member. The mother, who has terminal cancer, worries about her own diagnosis and how long she will live. The father, who is the primary caretaker, worries about if he can meet all of her needs while still providing for his family with young children. The children are stressed and anxious because they may not fully understand what this cancer diagnosis means, but they know that it has caused a lot of pain. Guilt is likely also a feeling that the parents of the family system are feeling. The mother knows that since her cancer has progressed so far, she will not be able to be around to see her children grow up and to guide them through life. She may also feel guilty about how her husband has to be her caregiver and has taken on so much extra burden. The father may feel guilty as well. He does not like seeing his wife in so much pain and may wish he could do something to alleviate it. These three concepts are a detriment to the family and need to be addressed through therapy.

Roles

The social worker acts as a mediator for much of this therapeutic relationship. While they come up with interventions, the family must be able to be on board with them and has to truly want to change. In many interventions, such as the FBDI exercise in the curriculum, the social worker's only role is to ask questions and encourage intentional listening. However, it is also important for the social worker to remain someone who is knowledgeable in the areas of difficulty that the family is encountering. The social worker must understand what cancer looks like at various stages and the struggles that come with them. This allows the family members to look to the social worker as an expert and someone who they can utilize as a resource. Finally, the social worker takes on the role of advocate. In a family, especially with children, members can feel like their voice is not being heard. During family therapy, the social worker needs to advocate for each member of the family to ensure that they feel safe to speak their opinion.

Structure of Curriculum

Week 1: Initial Engagement		
Goals/Objectives	Meeting the family and assessing the dynamics	
	 Ensure that dynamics are assessed both visually (by 	
	observations) and verbally (by what the family talks about)	
	Learn about the family history	
	 When was the family member diagnosed with 	
	cancer? How has coping been so far?	
	Name and identify what the family needs help with	
Purpose of the Session	The purpose of this session is to meet the family and understand	
	what the family dynamics look like in their home. The social	
	workers aim to understand what role cancer has played in their	
	interaction patterns and how it has changed since before the	
	diagnosis.	
Checklist of Items	- One printed copy of mini-MAC questionnaire	
	- Three printed copies of Perceived Stress Scale (PSS)	
	- Colored candies	
	- Questions to correlate with each color	

	- Deck of cards (for kids while parents are taking inventory)
	- Speaker for calming music
Psychoeducation	The social workers will introduce their roles in the relationship and
	the layout of the treatment plan. The purpose of each assessment
	tool will be explained as well.
Interventions/Activities	For mother (with cancer), complete the mini-MAC questionnaire.
	This was developed by Watson et al. as a way to assess fighting
	spirit, avoidance-denial, fatalism-stoic acceptance, helplessness-
	hopelessness, and anxiety (Czerw et al., 2021).
	For the rest of the family, complete the Perceived Stress Scale
	(PSS). This is a ten-question assessment concerning different
	situations affect feelings and perceived stress. The questions in this
	scale ask about feelings and thoughts during the last month.
	Go over family history with parents while children play cards.
	Colored Candy Activity
	- Each candy represents a question that the member of the family
	needs to answer. Each family member will get one of each color of
	candy. When they pick one to eat (or discard if they choose), they
	answer the question in front of the therapist/family members.
	Red: What makes you angry?
	 Orange: What are some things that you are passionate about?
	 Yellow: In the past, what has brought you joy?
	Green: What types of activities do you enjoy doing with your family?
	Blue: How do you relieve your stress/calm yourself?
	Brown: What are you thankful for?
	- The purpose of this activity is for the social workers to observe
	interactional patterns and observe the familial patterns. Does
	anyone interrupt frequently? Do all family members pay attention
	to each person speaking? Do the answers typically involve family
	time, or is it not mentioned?
	After this activity, ask how it made them feel. "Was it hard to come
	up with answers? Did you learn anything from your families
	answers?"
	Story-Telling Activity:

	The therapist starts with a prompt. Then, each member of the family says a sentence that goes along with it to create a story. For example, the therapist starts with the sentence: "There was a princess who lived in a castle." The rest of the family, one-by-one, adds a sentence to continue on. Let the story go on until there is no more to be said. Begin another story if needed. - The point of this activity is for the therapists to assess family dynamics. Does the family argue about what comes next in the story? Are there any patterns that the therapists can detect about the characters in the stories? After this activity, again, ask the family how they felt about it. Can they relate it to their own lives at all? Was it difficult to come up with the next sentence? Do you think you were on the same page as your family members? End with a question for the whole family: What would you like to
** 1	grow in throughout our time together?
Homework	Work on intentional listening. Make eye contact with one another. Ask each other questions and listen intently for the answer. This will help us in next week's session.
	Gratitude Homework: Each member of the family creates a list of things that they are grateful for, starting with each letter of the alphabet. For example, A = animals. Bring this to next week's session so you can share it with one another.

Week 2: FBDI and Working Through Feelings	
Goals/Objectives	 Enable the caregiver (husband) to effectively express her true feelings about his wife's diagnosis Create an environment in which the cancer patient (his wife) can listen intentionally to what her husband needs help with Initiate a way for the children to express their true feelings without the difficulty of finding the right words
Purpose of the Session	The purpose of this session is primarily focused on the parents in the family regarding their communication and feelings of the situation. FBDI is intended to allow true feelings to be shared without interruption or fear of judgment. The children will be in a different room working on a painting, which is intended to allow

	them to express their own emotions when they cannot find the words.
Checklist of Items	FBDI guided questionsPaints and canvasesSpeaker for calming music
Psychoeducation	Explain what FBDI is: Family-based dignity intervention (FBDI) is a psychological intervention taken from dignity therapy methods. It helps both cancer patients and their caregivers to strengthen their hope in themselves. It typically involves an interview with a therapist put into one video that they can share with their loved one who has cancer.
Interventions/Activities	Guided Questions – have the individual who is suffering from terminal cancer sit with their significant other. There are twelve specific questions that are asked during FBDI, taken from Hau Yan Ho et al. These include: 1. Tell me a little about your life history with your loved one; what are some of the most important and memorable times you had together? When did you feel most alive with your loved one? 2. How has your relationship with your loved one influenced your life? 3. What are some things you want your loved one to know about you, or to remember about you? 4. What do you think are your loved one's most important and meaningful accomplishments in life (family, career, community)? 5. What do you appreciate most about your loved one? 6. What do you think your loved one is most proud of you for, or appreciates about you? 7. Are there particular things that you want to thank your loved one for? 8. Are there particular things that you like to ask forgiveness for, or offer forgiveness for? 9. What teachings, advice, or words of guidance have you received from your loved one, and would like to pass on to other family members? 10. What are your hopes and dreams for future for your loved one, yourself, and your family? 11. In creating this permanent record, are there other things that you would like to include?

	12. Before the session ends, are there things that you would like to take time to say again? This will likely be a very emotional activity. It is important to stress that only the caregiver will be answering the questions, and the spouse who has cancer should stay silent and listen intentionally. Then, because this is an adaptation, the other person will answer the same questions. This time, the caregiver (husband) will have to be careful to listen and not speak or react. The children will be with another therapist in the other room. They will be completing their own paintings that depict their family, as well as reflect how they feel about their mother's diagnosis. This serves as a stress-reliever as well as allowing them to express themselves when words fall short. At the end of the painting session, the therapist will ask for an explanation and create interventions that will help with these feelings being experienced.
Homework	Work to be expressive with your emotions. Do not be afraid to feel your feelings. When something feels overwhelming, talk to a loved one about it. Do not simply bottle it all inside. Share one thing every night with a family member discussing what you need from them and asking what you can do for them as well.

Week 3: Mindfulness	
Goals/Objectives	Understand the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance of intentional mindfulness each day Compared to the importance
	Know how to use different strategies to implement mindfulness in daily life
Purpose of the Session	The purpose of this session is to show the family three different ways to practice mindfulness. This way, they have the tools that they need in order to implement these practices on their own.
Checklist of Items	 Blankets and pillows Tea/warm beverage of choice Speaker for relaxing music Pieces of chocolate
Psychoeducation	Explain the purpose and importance of mindfulness during stressful times. Mindfulness is a type of meditation in which you focus on being intensely aware of what you're sensing and feeling in the moment, without interpretation or judgment. It can help to improve

	stress, anxiety, pain, depression, insomnia, among much more. (https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/mindfulness-exercises/art-20046356)
Interventions/Activities	Body scan meditation: Lie on your back on the pillow and under the blankets that the therapist have provided. Focus on being truly present. Listen to every sound and feel everything that is touching you. Be aware of all sensations, thoughts, and emotions. Focus on each part of your body and how it feels.
	Mindful eating: Chocolate – pay attention to what you are holding, notice how it feels in your hands. Once you notice the texture, think of the weight, color, etc. Then bring your awareness to the smell. Finally, you will eat the chocolate, but you will eat it slowly and with concentrated attention. Notice how it tastes on your tongue as well as the texture of it in your mouth. This exercise is intended to ground you and focus on only being in the present.
	Kindness meditation: Begin in a comfortable seated position. Close your eyes and bring to mind someone who you respect and admire. Notice how you feel when you think of this person. Come up with something that would make them happy. Next, think of a family member around you. Determine what you can do to make their day better. Finally, think of someone who has made you frustrated lately. What can you do to help them out and make their day?
Homework	Random acts of kindness based on the kindness meditation exercise. Who was the person you thought of that made you frustrated? Do one thing that would make their day better. Make sure you are practicing mindfulness at least once a day for
	five minutes. Come up with a schedule for your week. For example, when you first wake up in the morning before you brush your teeth would be a great time.

Week 4: Communication and Trust	
Goals/Objectives	Increase trust between all family members
	 Foster an environment in which open communication is
	easy and automatic
	• Examine previous assumptions about other family members

Dymaga of the Cassian	These three exercises serve to first examine what we think others
Purpose of the Session	
	are thinking, then understand our own thoughts, and finally build
	the courage to express them.
Checklist of Items	- Bowl of topic suggestions
	- Notebook
	- Pen
	- Cones
	- Blindfold
Psychoeducation	One of the most important strategies is figuring out how to
	communicate with one another. The mother suffering from terminal
	cancer should be able to convey what she needs for support, while
	the father should know how to do the same. The children need to
	understand their own feelings and how to interpret them.
Interventions/Activities	Mirroring Activity – This is a role-playing activity. The family will
	split into pairs, and the goal of this exercise is to realize how they
	are being individually perceived by their family members. The
	family will take 5-10 minutes to have a conversation on a random
	topic of their choosing. Their goal is to act as if they were the
	individual in front of them. As they continue to act out each other,
	the goal is to reach common ground of communication and
	awareness.
	awareness.
	Expressive Writing: This is writing that comes from our core. It is
	personal and emotional, and doesn't regard spelling, punctuation,
	and grammar. It simply expresses what is on one's heart. This
	exercise should enable all members of the family to examine their
	true feelings, which allows them to share them with one another.
	The family will be given one prompt: How do you feel about the
	cancer diagnosis? They will be given 15 minutes to write nonstop.
	If one runs out of things to say, they should repeat what has already
	been written until the time is up. The writing will not be shared
	with one another and simply serves to help one interpret their own
	feelings.
	Trust-Building Exercise: blind-folded obstacle course. The
	therapist will set up cones around the room with a starting line and
	a finish line. The family will split into pairs. One person in each
	pair will wear a blindfold while the other is serving as their guide to
	get through the obstacle course. The blindfolded person needs to
	trust their guide completely in order to make it to the end.

Homework	Each day, when you are eating dinner, share one thought or feeling
	you had during the day. Make sure you are honest and not
	concerned about the judgement passed between family members.
	Our goal with trust building is to create better open communication
	between members of the family.

Week 5: Evaluation and Closure	
Goals/Objectives	Evaluate progress and look ahead to what the future looks like after therapy has ended.
Purpose of the Session	Ensure that each member of the family feels like they have made progress and feels confident in continuing this trend. Therapists and clients will also discuss the final wrap-up and closing ceremonial activities.
Checklist of Items	One printed copy of the mini-MAC inventoryThree printed copies of the Perceived Stress Scale (PSS)
Psychoeducation	Explain what termination of services means as well as the importance of setting long-term goals for after therapy.
Interventions/Activities	For mother (with cancer), complete the mini-MAC questionnaire once again. The therapists will score it and evaluate how much progress has been made throughout therapy. For the rest of the family, complete the Perceived Stress Scale (PSS) again. The therapists will score them and evaluate how much progress has been made throughout therapy. Ask clients if they would like to be connected to any other resource when done with the session, such as support groups. The therapists will come to the next session with a list of requested and recommended resources.
	Together, create long-term goals for after therapy. This includes each member of the family. Ask everyone intentionally about what they would like to continue doing rather than let one member overpower the others.
	 Give ideas for strengthening family connections, such as Being intentional to eat dinner together every night, even with the craziness of schedules

	 Set aside time for conversations without distractions, both as a family and one-on-one Communicate how you feel about one another. Tell each other "I love you" Make sure to spend fun time with one another too, such as board game nights and watching a movie together
Homework	Before leaving, tell the therapists your favorite snacks and drinks.
	Come to next session prepared to celebrate!

Week 6: Final Wrap-Up and Closing Ceremonial Activities	
Goals/Objectives	 Develop recognition and appreciation for progress made during therapy Give clients closure Empower clients to see their strengths and all that they have learned Help clients to feel confident in their abilities to continue growth even after therapy has ended Effectively terminate the therapeutic relationship
Purpose of the Session	The purpose of this session is to give clients a sense of closure as well as celebrate the progress that has been made. The family will discuss what they will continue to work towards in the future. This session will also allow them to understand their own strengths and affirm that they will continue to be successful after the therapeutic relationship has ended.
Checklist of Items	 Snacks and drinks Personal journals with cool pen Resources that the family has requested from the last session
Psychoeducation	Define the term empowerment: the process of becoming stronger and more confident, especially in controlling one's life and claiming one's rights.
Interventions/Activities	Discuss the strengths of the clients as they continue forward in their journey. Help them to see strengths even when they cannot see them on their own. Help the clients to see what progress they have made by sharing the results of the assessment tools with each individual person in the family.

	 Give a list of positive affirmations that the clients can utilize after therapy. These include, but are not limited to, repeating the words: I am strong. I am grateful for everything I have. I have an amazing support system and will lean on them for everything. I love and accept myself for who I am. I have many talents, gifts, abilities, and strengths. I am not defined by my circumstances or my past. Party!
Homework	Continue practicing everything that you have learned in our
	sessions together.

Transitions/Endings

In order for termination of a therapeutic relationship to be successful, the social worker and the clients need to agree that goals were met, and progress has been made. The client should feel as though they accomplished what they came to therapy for. For this family, that involves coping with a drastic and difficult change in their lives. During the termination process, the social worker worked to create a smooth transition into the families lives after therapy. This was done through a variety of methods. One technique was bringing a list of resources for the family to utilize if needed after the therapeutic relationship has ended. An example of such a resource could be a spouse bereavement support group for when the mother/wife has passed on in this family. The social worker also found it important to instill confidence in the family members that they were able to continue to make progress even after the social worker is not meeting them every week. This was done through three methods: strengths discussion, assessment tool progress, and positive affirmations.

A discussion of the client's strengths is based on the strengths perspective that is utilized in social work. The social worker helps the clients to see where they are gifted and how they can utilize those gifts to continue growth. Another method that the social worker implemented was sharing the progress made with each member of the family by comparing their assessment tool results. The therapist chose to utilize this method because it allowed each member to directly see how they have grown throughout therapy when they see improvement within their results. The social worker will make sure to sit down with each client and explain the numbers that they see to avoid misinterpretation and enable the clients to see their full progress. Finally, the social worker chose to give the family a list of positive affirmations to repeat until they believed it. It is a tool intended to help with the confidence of continual progress as it equips the family to believe in who they are as an individual, which is then reflected on the family system.

Methods for Assessing Outcomes and Evaluation of Practice

The social worker chose to use two different methods for assessing outcomes and evaluation of practice in this family therapy because they are in different circumstances within the same family. For the family member with cancer, the mother/wife, the researchers chose to use the mini-Mental Adjustment to Cancer tool, also known as the mini-MAC. This is a well-recognized tool in measuring coping strategies among cancer patients and asks a total of twenty-nine questions related to these strategies. It is based on the Mental Adjustment to Cancer scale, which was constructed by Watson et al. (Czerw et al., 2021). Because the client has very advanced cancer, it was important to recognize the ways that she has been coping and identify how they can be adjusted throughout the course of therapy.

The therapists also decided to use the Perceived Stress Scale, or PSS. They chose this as it is designed to assess how unpredictable, uncontrollable, and overloaded respondents feel in

their lives (Cohen et al., 1983). It also asks questions in a way that is easy for all ages to understand. Because the therapists administered this assessment to members of the family ranging from 11-years-old to 40-years-old, they had to ensure that the assessment was able to be comprehended with all age groups. This assessment is useful because it measures the degree that respondents find their situation stressful, which has improved throughout therapy.

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