

# Dreamweaver Foundation Impact Study 2018

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## EXECUTIVE SUMMARY

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Dreamweaver Foundation describes their work as “...fulfill(ing) lifelong dreams for terminally ill seniors in need.” This impact study was designed to provide evidence of how the Foundation is making a difference in the lives of the dreamers and their families.

This study applied a systematic and objective approach to understanding the impact of the Dreamweaver Foundation by conducting and analyzing interviews with a representative group of dreamers and their families. The richness of their experiences was captured through these interviews and analyzed to identify themes of impact. In order to provide a solid foundation for the interview process, the study also included analysis of client data, review of existing research, conceptual frameworks, and interviews with key informants.

### Client Data

#### *Nominator Characteristics*

From 2016 to 2017, Dreamweaver Foundation received 113 nominations from across Nebraska and Iowa. Nearly half of the 113 individuals were nominated by professionals, of whom 41% were hospice representatives, 39% residential facilities, 10% healthcare settings, and 8% senior centers.

#### *Dreamer Characteristics*

At the time of the study, 55 nominees had completed their dreams. Just over two thirds of the dreamers were female (68%). Dreamers had a variety of diagnoses, although cancer was the most prevalent condition (20%), followed by dementia (6%) and renal failure (6%). About four in five of the dreamers served were from the Omaha metropolitan area, which included of Douglas, Sarpy, and Pottawattamie counties.

### Review of Research

The research and theoretical frameworks provide a lens through which to examine the impacts of the program. “Quality of life” and “positive dying” are key concepts in the research within the following frameworks:

- *Palliative care* approaches that strive for multidimensional quality of life for individuals are a good investment for the individual, the family, and society. One critical area of quality of life to address is psychosocial health, as it is both a necessary ends for good quality of life. and it is a predictive factor in other elements of quality of life like symptom distress.
- *Anticipatory grief* is a condition that is experienced by both dying individuals and their families. To promote psychosocial quality of life, interventions must assist families in coping with anticipatory grief. This process is especially important in helping terminally ill individuals to accomplish their final developmental task of ego integrity, which will promote a positive dying experience.
- *Success in palliative care* lies in facilitation of openness and acceptance of the dying process in a generative way through reminiscing, relationship-building, ego expression, and cultivation of hope and resilience.

- Evidence suggests that activities that reinforce identity and self-concept, acknowledge the incredible significance of interpersonal relationships, and cultivate reminiscence and life narrative story-telling produce hope, resilience, maturity, and growth in the end of life—all *factors related to psychosocial health and positive dying.*

### **Key Informant Interviews**

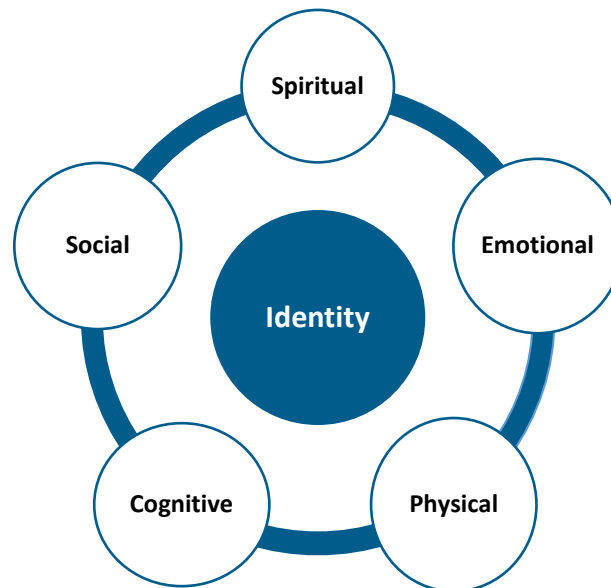
Key informants represented organizations who were involved with Dreamweaver Foundation as either nominators or executors of the dream experience. Agencies represented included Florence Home, AseraCare Hospice, Van Mauer, VIP Limo and Carson Wealth. Results of the key informant interviews indicated that the program was observed to impact dreamers' quality of life, especially their psychosocial well-being, which was consistent with the literature.

Key informants stated that dreamers had a feeling of being recognized and cared for, were distracted from their illness, were energized, were happy, and were given hope and a sense of peace. They cautioned, however, that impacts of the dream were influenced by the symptoms of the dreamer's diagnosis.

Key informants also observed positive impacts on dreamer's family and friends. They observed the value in providing the family with an opportunity to reconnect through the dream experience, to capture a positive memory of their loved one, and to feel a sense of peace that is achieved from observing their loved one achieve their dreams.

### **Dreamer Interviews**

Interviewees consisted of former Dreamweaver Foundation dreamers or their close family members in order to capture a full range of the program's impact. The 10 interviewees were selected for their representation of the variety of characteristics, backgrounds, and dream experiences. The analysis of the interviews was structured around the following theoretical model of the dimensions of quality of life.



During the interviews, the dreamers or family members were asked to share their journey with the Dreamweaver Foundation, starting with their situation and nomination, moving to deciding on, planning and experiencing the dream, and ending with a reflection on the dream's long-term impact or legacy.

### **The Need**

A terminal diagnosis sends both dreamers and their families into turmoil. Dreamers are burdened, isolated, and even redefined by their physical and mental limitations. Families are overwhelmed by making critical medical care decisions and reconciling the future loss of a loved one.

- Identity: Dreamers are being redefined by their illnesses, but are taking time to reflect on their priorities, including the people and things most important to them and a focus on making bad things better.
- Cognitive/Physical Health: Dreamers are dealing with medical, mental and mobility issues. Families are struggling to make tough decisions and care for their loved ones.
- Emotional/Psychosocial Health: Dreamers and their families have experienced many recent losses in their lives. Families are overwhelmed with dealing with the illness and terminal diagnosis.
- Social Health/Relationships: Dreamers are often isolated by their illness. The stress of the situation can heighten family conflict.
- Spiritual Health/Significance: A life-end dream is not among their priorities as they deal with day-to-day challenges.

*“..for us it was like we were in this huge black hole, and they pulled us out for a little while. A reprieve for a time.”*

### **The Dream's Impact**

The dream experiences produced intense emotional and social impacts on both the dreamers and their families. In some cases, the significance of the experience transcended verbal description.

- Identity: The dream experience brought dreamers back to their old selves and offered a chance to re-experience past experiences and passions.
- Cognitive/Physical Health: The dream experience provided an opportunity to be out doing normal things. Dreamers relished the chance to fit in, but also worried that their illness might restrict their participation in the dream activities.
- Emotional/Psychosocial Health: The dream experience evoked a wide range of emotions and comments. They included apprehension, anticipation, excitement, happiness, feeling relaxed and distracted from the illness, finding a reprieve from stressful life circumstances, and finally peace and closure.
- Social Health/Relationships: The importance of relationships and connections were evident in the interviews. The dream experience made the dreamers feel recognized and valued. For both dreamers and their families, the dream connected them to their loved ones and created cherished memories.
- Spiritual/Significance: While a few of the dreamers and family members described “God moments” during their dreams, others identified them as “once in a lifetime” and “last chance”

events. Additionally, a number of those interviewed explained that they just didn't have the words to describe the dream's significance.

*"There was life in him, it was like...  
Somebody kindled a spark and there was life. He came back to life."*

### **The Dream's Legacy**

While dreamers experienced renewed motivation and a sense that life isn't over yet, family members identified the lasting impact of the dream experience to be the creation of positive memories captured in cherished photographs.

- Identity: After the dream, some dreamers confirmed that they had more confidence in themselves.
- Cognitive/Physical Health: Some dreamers cited a motivation to be more active—pursuing hobbies, volunteering, and getting out in their communities.
- Emotional/Psychosocial Health: Hope was the most commonly mentioned emotion. Dreamers reported being lifted out of a "funk", having a little "zing" in their step, and having a renewed sense that life isn't over yet.
- Social Health/Relationships: The creation of new positive memories was mentioned by all the dreamers and family members. The dreamers described or shared pictures of their dream experiences and reflected on the powerful legacy that the pictures provided.
- Spiritual / Significance: The dreamers and their families described themselves as humbled and grateful. Some of the dreamers even incorporated elements of their dream into their dying wishes, including being buried in their dream outfit and having their ashes spread at their dream location.

*"... the grandkids were playing, the great grandkids were playing.  
So I think it was really good for her to see, 'This came from me, this is my legacy.'"*

### **Dreamweaver Foundation Strengths and Challenges**

While not asked specifically to evaluate their experience with the Dreamweaver Foundation, the interviewees were quick to share thoughts about their dream process. Input from interviewees translated into some powerful strengths and potential challenges for the Foundation.

#### *Strengths*

Dreamweaver staff were described as caring, thoughtful and angelic. The dreamers and family members cited powerful and continuing connections with staff members, describing their work as "walking by their sides." They appreciated the responsiveness, follow-through, and attention to the dreamer's needs. The dream experiences exceeded expectations and motivated a desire to reciprocate by spreading the word, being involved in fundraising, and making donations themselves.

#### *Challenges*

Interviewees expressed a skepticism about the validity of the Dreamweaver Foundation's offerings. They described their initial thoughts as it being a scam or a joke or just "too good to be true." On the operational level, interviewees shared the challenges of coordinating the timing of a dream with the condition of a dreamer. One dreamer also shared the discomfort experienced when introduced by a

dream partner as someone who “won’t be with us much longer.” This ran contrary to the sensitivity demonstrated by the Foundation staff with the positioning of the program as a “life-long” dream rather than a “life-end” dream.

## PROGRAM DESCRIPTION

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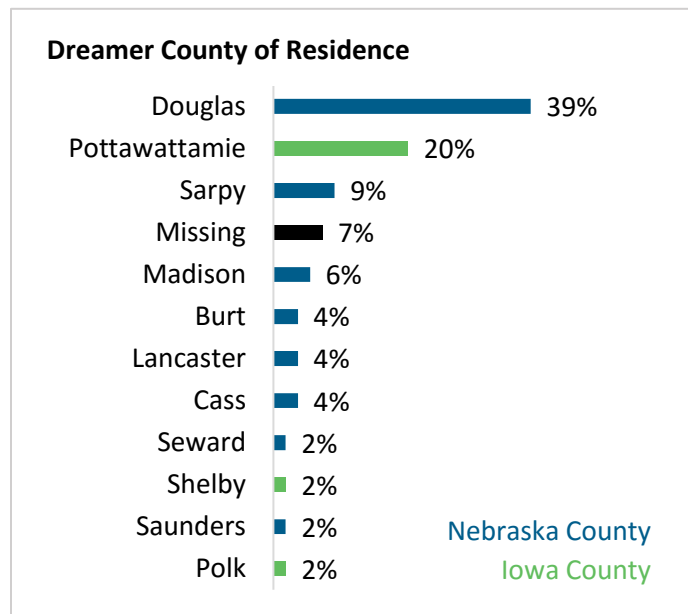
Dreamweaver Foundation describes their work as “...fulfill(ing) lifelong dreams for terminally ill seniors in need.” This impact study was designed to provide evidence of how the Foundation is making a difference in the lives of the dreamers and their families.

### Nominator Characteristics

Terminally ill individuals above the age of 55 who are unable to afford their dream are nominated by others to receive that dream from the Dreamweaver Foundation. From 2016 to 2017, Dreamweaver received 113 nominations from across Nebraska and Iowa. Nearly half of the 113 individuals were nominated by professionals, though one in five were nominated by family or friends. Of those professional nominators, 41% were hospice representatives, 39% were residential facilities, 10% were healthcare settings, and 8% were from senior centers. Of the nominators who were family and friends, about 5% had been the recipient of a dream from Dreamweaver Foundation themselves.

### Dreamer Characteristics

Of those 113 individuals nominated, 55 had completed their dream at the time of the study. Just over two thirds of the dreamers were female (68%). Dreamers had a variety of diagnoses; cancer was the most prevalent condition (20%), followed by dementia (6%) and renal failure (6%). About four in five of the dreamers served were from the Omaha metropolitan area, constituted from Douglas, Sarpy, and Pottawattamie counties. The remaining dreamers resided across rural Nebraska and Iowa. About 76% of dreamers were from Nebraska compared to 24% from Iowa.



## THEORETICAL FRAMEWORK

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The theoretical framework is drawn from academic literature on interventions in end-of-life care. The literature provides a foundation upon which Dreamweaver Foundation can empirically justify their course of intervention. Additionally, the theoretical framework provides a lens through which we might approach and examine the potential impacts of the program. The following literature was integral to conceptualizing the program, developing the evaluation, and interpreting the outcome results.



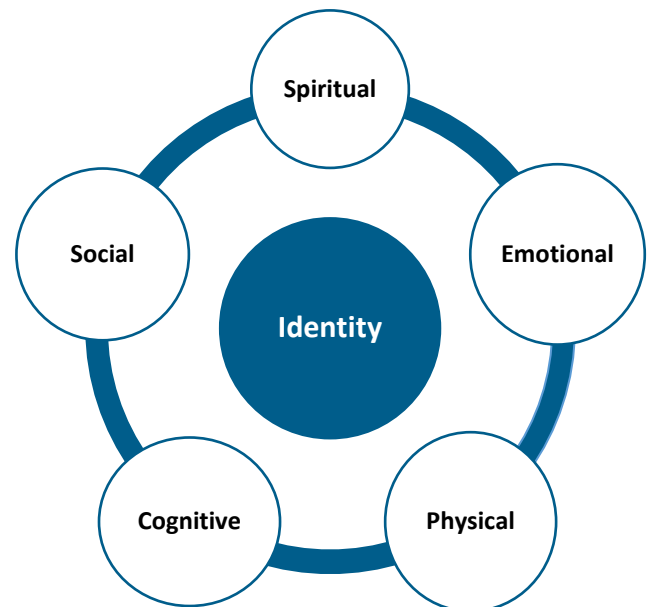
## Palliative Care Approach

Palliative care is an approach to end-of-life care that treats the whole person to improve the patient's quality of life, while reducing the strain and burden on family members and caregivers. The goal of palliative care is to provide "effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures (Miller & Ryndes, 2005, p. 2). Palliative care is not intended to stop or ignore the process of dying, but to respect it and nurture the person experiencing the transition towards it. In a sense, palliative care is seeking to foster an experience of positive dying, which has been defined as "an individual attaining a sense of peace, integrity, and personal healing despite the effects of a life threatening illness" (Nakashima & Canada, 2005, p. 111).

Not only is a palliative approach to end-of-life care beneficial for the individual and their caregivers, it is an economic decision. A palliative care approach is a good public health investment as it reaches a comparatively large portion of the population, has a profound impact on the individual, and has low to moderate cost as compared to other commonplace health interventions like flu vaccination campaigns and organ transplants. In return, costs on the healthcare system are reduced when futile medical interventions for the dying person are avoided. Additionally, future health costs may be lower because caregivers have fewer aversive health outcomes from sustained stress and grief (Millard & Ryndes, 2005).

## Multidimensional Quality of Life

The key objective of palliative care is to increase patient quality of life during the dying process. Quality of life is multidimensional and extends beyond physical functioning, which is generally the primary focus in other approaches to end-of-life care. Other significant aspects of quality of life include emotional, social, and spiritual health, all of which are threatened by a terminal illness. Having a high quality of life can produce fewer or less severe symptoms (Miller & Ryndes, 2005), which eases the dying process and emotional strain for loved ones.



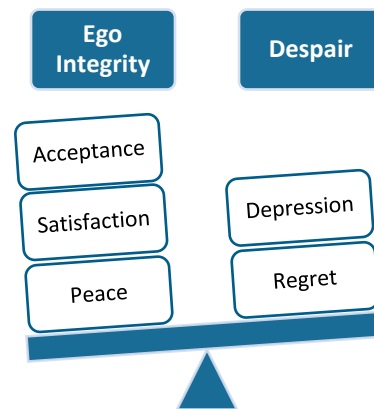
One study found that depression, in addition to physical symptoms, was an independent predictor of quality of life (Garrison, Overcash, & McMillan, 2012). Approximately 45% of people receiving palliative care treatment experienced depression in one study. Those who experience depression often have exacerbated symptoms of pain and fatigue, which can further reduce quality of life (Garrison, Overcash, & McMillan, 2012). Therefore, attending to the psychosocial needs of individuals can promote multiple dimensions of quality of life.

## Antagonists to Psychosocial Quality of Life

Facing a terminal illness is strongly associated with "profound psychosocial and spiritual crises that manifest as depression, heightened anxiety, and hopelessness" (Nakashima & Canada, 2005, p. 110). As individuals experience the consequences of terminal illness, they often lose their ability to function autonomously and often transition to a nursing care residence, which can further contribute to the loss of ego strength (Brownie & Harstmanhof, 2012). Anticipatory grief is the "range of emotional responses towards anticipated loss" (Cheng, Lo, & Woo, 2013, p. 103). This form of grief can be experienced in anticipation of ones' own death or the death of a loved one, and includes not only anticipation of the loss of life, but also other associated losses including loss of functioning, roles, identity and losses in the future, including hopes, dreams, and plans (Cheng, Lo, & Woo, 2013). Studies of anticipated grief found that those who suffer grieved the loss of their own existence, faced fear of dying alone, and experienced a sense of hopelessness. Additionally, the loss of the physical self, including functional abilities, is often accompanied by secondary losses of self-esteem and identity (Cheng, Lo, & Woo, 2013).

When an individual experiences anticipatory grief at the end of their life, that grief aligns with the final developmental task of life according to Erikson's theory of psychosocial development. Erikson's theory outlines a lifespan approach to understanding how people develop throughout their lives. The eight stages of development begin in infancy and conclude in nearing death. The final developmental task of ego integrity versus despair, is initiated after a life event that insinuates mortality, such as receiving the diagnosis of a terminal illness.

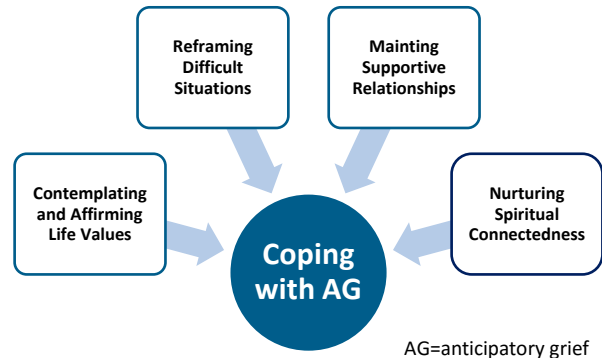
After experiencing a life event that indicates mortality, individuals begin an experience called "life review" which will concludes in either accomplishing ego integrity or falling into despair. During life review, individuals "[are] reflecting on the lives they have led while preparing for the inevitableness of death" (Goodcase & Love, 2016, p. 355). Achieving ego integrity is characterized by self-acceptance, tolerance towards others and a sense of life satisfaction. Often, those who achieve ego integrity have "found meaning in their lives, feel they have achieved important goals, and have found peace prior to death" (Goodcase & Love, 2016, p. 355). Inability to achieve ego integrity can result in despair, characteristics by depression, inability to accept themselves or others, and anger.



## Supporting Psychosocial Quality of Life

Psychosocial health can be promoted through individuals and their loved ones coping well with anticipatory grief. Activities that reduce anticipatory grief are important to reduce or prevent depression, reduce strain on loved ones, and promote successful achievement of ego integrity.

Studies have found that those experiencing anticipatory grief cope through several strategies, including contemplating and affirming life values, reframing difficult situations for a new understanding, maintaining supportive relationships, and nurturing a spiritual connectedness. Researchers conclude, "emotional acceptance is associated with coping and spirituality, and determines whether the patient could transcend suffering in anticipatory grief" (Cheng, Lo, & Woo, 2013, p. 104). Therefore, providing mechanisms to affirm live values, renegotiating meanings of past difficulties, and supporting relationships are invaluable approaches to simultaneously decreasing anticipatory grief and solidifying ego integrity.



One powerful approach to reducing anticipatory grief is through reminiscence and processing of life-story narratives. "Life story narratives can help older patients find insight and wisdom and encourage adaptive psychological processes of hardiness, perceived control, and self-efficacy" (Cheng, Lo, & Woo, 2013, p. 107). These benefits can help to overcome the grief of losing functioning and autonomy and can facilitate the reframing of current experiences. This process reaffirms the individuals' sense of identity and provides the means to express the emotions of their loss through recounting past experiences (Cheng, Lo, & Woo, 2013).

### Summary

Research suggests that palliative care approaches that strive for multidimensional quality of life for individuals are a good investment for the individual, the family, and society. One critical area of quality of life to address is psychosocial health as it is both a necessary ends for good quality of life, and effects other elements of quality of life like symptom distress.

Anticipatory grief is a condition that is experienced by both dying individuals and their families. To promote psychosocial quality of life, interventions must assist families in coping with anticipatory grief. This process is especially important in helping terminally ill individuals to accomplish their final developmental task of ego integrity, which promotes a positive dying experience. Accomplishment of ego integrity promotes acceptance, tolerance, and peace in death. Failure to accomplish ego integrity may mean falling into despair, depression, unacceptance, intolerance, anger, and fear of death.

Success in palliative care lies in facilitation of openness and acceptance of the dying process in a generative way through reminiscing, relationship building, ego expression and cultivation of hope and resilience. Evidence suggests that activities that reinforce identity and self-concept, acknowledge the incredible significance of interpersonal relationships, and cultivate reminiscence and life narrative storytelling produce hope, resilience, maturity, and growth in the end of life—all factors related to psychosocial health and positive dying. Dreamweaver Foundation is a palliative care approach that attempts to elevate terminally ill individuals and their families from depression and despair, hopefully bringing them nearer to acceptance and peace.

## **METHODOLOGY**

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This study applied a systematic and objective approach to understanding the impact of the Dreamweaver Foundation by conducting and analyzing interviews with a representative group of dreamers and their families. The richness of their experiences was captured through these interviews and analyzed to identify themes of impact. In order to provide a solid foundation for the interview process, the study also included analysis of client data, review of existing research, conceptual frameworks, and interviews with key informants.

### **Sampling**

Interviewees consisted of former Dreamweaver participants and/or their closest family members. We interviewed a mixture of dreamers and caregivers out of both necessity and design. It was at times a necessity to interview caregivers due to dreamer participants passing away. It was also per design to capture a full range of the program's impact on the dreamers themselves and those closest to them. Interviewees were recruited for participation by Dreamweaver Foundation staff out of sensitivity to the life circumstances surrounding their involvement with the organization. Participants were purposefully selected to represent a variety of characteristics, backgrounds, and dream experiences.

### **Question Development**

Questions were developed based upon the literature and results of key informant interviews. Five key informants were interviewed, all of whom were professional stakeholders with first-hand experience working with dreamers and the Dreamweaver program. Interviewees were asked about their observations of the impact Dreamweaver had on participants prior to, during, and after the dream experience. Additionally, results of the literature review were shared with the interviewees who were asked to reconcile the findings with their practical experience. Key informants represented organizations who were involved with Dreamweaver Foundation as either nominators or fulfillers of the dream experience. Agencies represented included Florence Home, AseraCare Hospice, Van Mauer, and Carson Wealth.

Results of the key informant interviews indicated that the program impacted dreamers' quality of life, especially their psychosocial well-being, which was consistent with the literature. Key informants stated that dreamers had a feeling of being recognized and cared for, were distracted from their illness, were energized, were happy, and were given hope and a sense of peace. They cautioned, however, that impacts of the dream were dictated by the symptoms of the dreamer's diagnosis. Key informants agreed that the dreams had positive impact on dreamers' symptom distress during the dream, self-esteem and expression of personal identity, and emotional health. They did not believe the dream had impact on the dreamers' functional or independence, and they were unsure about the impact on the religious/spiritual or cultural health of the dreamer.

Key informants also observed positive impacts on dreamers' family and friends. They observed the value in providing the family with an opportunity to reconnect through the dream experience,

providing the family with a positive memory of their loved one, and a sense of peace that is achieved from observing their loved one achieve their dreams.

### **Interviews**

Dreamweaver staff obtained consent to participate from interviewees, coordinated interview times, and introduced the interviewer at the start of each face-to-face interview. One interviewer met with five dreamers by phone and five in person at the location of their choosing. Interviews followed a semi-structured format of six questions and additional sub-questions. Interviews lasted from 20 to 90 minutes each and were recorded by a digital audio-recording device.

### **Analysis**

Audio recordings were transcribed using transcription software. Transcription data were then transferred to Excel for coding. Two evaluators independently analyzed the data looking for codes and themes. After initially coding the data, evaluators met to reconcile their codes for consistency. These consistent codes were then applied universally across the data.

### **Limitations**

In this project, the evaluators used qualitative interviews to explore the impact of experiencing a Dreamweaver Foundation dream. The goal of qualitative research is to fully describe a *phenomenon* and then interpret the findings for their underlying meaning. To capture a phenomenon in its entirety, researchers collect data continually until the data reaches a point of *saturation*, meaning no new concepts or themes emerge (Atieno, 2009). Rather than pursuing interviews to a point of saturation, the research team conducted and analyzed 10 interviews with an intentional mix of dreamer characteristics. Therefore, it is possible that the findings are not an exhaustive picture of Dreamweaver's impact.

Due to the degree of subjectivity of language, it is not certain the interview responses were interpreted as intended (Atieno, 2009). While the interviewees may have used certain words to communicate their experience, the evaluators may bring a different interpretation to that language. . To minimize this limitation, the evaluators utilized the analytic technique of two distinct coders of interview transcripts in an attempt to transcend the subjectivity the evaluators brought to the analysis.

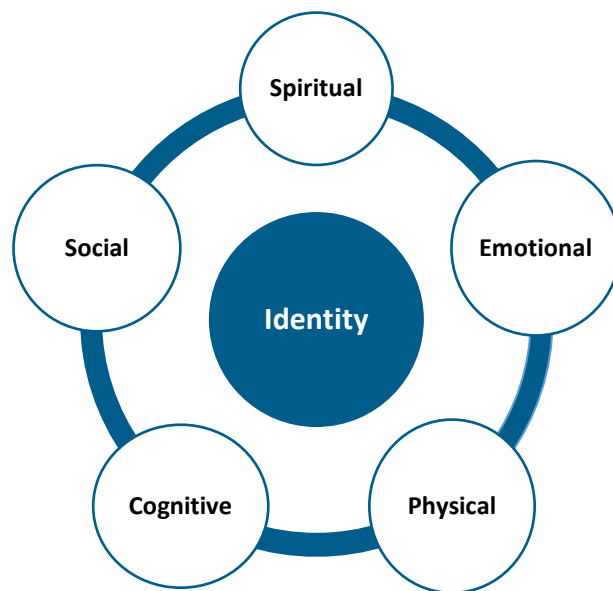
Finally, the use of a qualitative approach always bears the limitation of lack of generalizability. Unlike quantitative approaches, qualitative research does not undergo tests of statistical significance to understand if the findings were unique to this situation, due to chance, or likely to be true for a larger population. This means that we are unable to assume that the findings of the Dreamweaver's Impact study would be true for other individuals receiving a life-long dream at the end of life (Atieno, 2009). We can be confident, however, that the results indicate the specific impact that Dreamweaver Foundation has made on their past dreamers.

## FINDINGS

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During the interviews, the dreamers or family members were asked to share their journey with the Dreamweaver Foundation, starting with their situation and nomination, moving to deciding on, planning and experiencing the dream, and ending with a reflection on the dream's long-term impact or legacy. Throughout this section, the bulleted statements are quotations from the interviews with the dreamers and their families.

The findings from this impact study are presented below and organized within the framework of the quality-of-life dimensions. Along with the traditional palliative care's focus on patients' life beyond physical functioning, the dreamer and family member interviews spoke to how the Dreamweaver Foundation impacts those same identity, emotional, social and spiritual needs.



## THE NEED

Terminal diagnoses send both dreamers and their families into turmoil. Dreamers are burdened, isolated, and even redefined by their physical and mental limitations. Families are overwhelmed by making critical medical care decisions and reconciling the future loss of a loved one.

### Identity

#### **Dreamers are redefined by their illnesses.**

- He felt frustrated and definitely **homebound** because he was not that person. My husband was **never sick a day in his life**. I can never recall him being in bed sick.
- I've always been a very **extroverted person**, and there was no limit to the things that I would do or at least be found trying, if I wanted to do it, if I was interested. **Now that I'm disabled**, I can't do that.

### **Dreamers reflect on their priorities.**

- I got to know and understand what it is to live and know a little bit about myself and what I wanted and what was no longer important to me in my life. ...I really **concentrate now on the people and things that are important in my life** that have been through my life all the way despite the hard times, despite the good times.
- You get a kind of look in the window so to speak and **not just always see the good things, but the bad things and how they make things better**. And that's what I try to focus on.

### **Cognitive/Physical Health**

#### **Dreamers deal with medical, mental and mobility issues.**

- My dad he was **wheelchair bound**. And he was getting increasingly weaker and weaker. And... sometimes, he just, he wasn't in his right mind.
- That's kinda where the **depression is setting in, is because her balance**, she uses walking sticks a lot.
- Because with **dementia**, we just didn't know how long I have, and everything, so....
- She was in **Stage 5 kidney failure**, renal failure. And she had already opted not to do dialysis.

#### **Families struggle to make tough decisions and care for their loved ones.**

- In order to confirm cancer, they would have to do the exploratory biopsy which again involved surgery. And so the likelihood of her surviving that with her other medical issues, her heart issues, they **didn't think she was a good candidate**. Plus, if they would've confirmed lung cancer, they couldn't have provided any chemo or radiation because her kidney was already failing.
- **I'm really, really tired** and it's tiring here with dad 'cause right now he's nice and calm, but most days he's not like that and the mental fatigue of watching him going through that every single day.

### **Emotional/Psychosocial Health**

#### **Many of the dreamers and their families have experienced many recent losses in their lives.**

- I took care of my **mother-in-law during hospice care**. Then my **brother passed away** and six months later, my **husband passed away**. And then I was diagnosed. So I got a little understanding as to what is involved with living and dying.
- I counted anywhere from **13 people that I had lost ... since 2009**.
- **Mom passed away unexpectedly** last April, and Dad has a terminal diagnosis.

#### **Families are overwhelmed in dealing with the illness and terminal diagnosis.**

- I used to work two jobs. I had to quit one full-time and just work it part-time and .... I stay here during the day and then about 10 o'clock at night when (my kids) start rolling in I take off and go home. **I'm just tired**.
- When trying to identify a dream, I was at a complete blank. I was like, um... And I don't know if it was just because **I was overwhelmed with everything going on...**
- Our journey now when we brought him home is to find a way to slowly let him go, but **that's been very, very difficult**.

## Social Health/Relationships

### **Dreamers are isolated by their illnesses.**

- She doesn't drive. She only gets out, basically when I take her. *Very isolated, very lonely. Secluded.*
- We just didn't, never went out, because we didn't... *all of our friends are gone.*
- I actually *don't go much of anywhere*, because I'm disabled. And I don't have very much vision. I'm pretty much home, unless I'm going to a medical appointment or maybe to the supermarket.

### **Family conflict can resurface.**

- I don't talk to my (step) kids. I send them Christmas cards and Christmas presents and the grandkids, and birthday. But *they don't call*. They don't come and see me. And that hurts more than anything.
- When she was married to my brother, *she wanted my brother all for herself*. She came into a relationship where there were three of us. She doesn't like to share her life with others.
- My *step-dad doesn't do anything with her*. And that's probably the most frustrating thing and upsetting thing especially to her is that she doesn't even feel that her husband wants to do anything with her anymore.

## Spiritual Health/Significance

### **Dreamers and families are overwhelmed by the gravity of their situation.**

- What do you want to do at the end of your life? You always think about those things, but when it's the end of your life, it's hard to say... I don't know 'cause *nothing really matters at this point*.
- You wanna do something like that, but then it just never transpires because you don't, it's *not on your radar*. Spending time with my mom was on my radar, making sure she was comfortable, making sure she was happy.
- *There's a need for people ... to reach out, help someone go through this* because you feel alone. And you're not sure if you can get out of bed or you're not sure if you're gonna live for today or tomorrow.

## **THE DREAM'S IMPACT**

The dream experiences produced intense emotional and social impacts on both the dreamers and their families. In some cases, the significance of the experience transcended verbal description. The dreams provided opportunities for the dreamers and their family to revisit the times before their illness. Personalities shone through, pride of appearance, old memories surfaced, and illness fell into the background.



## Identity

### **The dream experience brought dreamers back to their old selves.**

- Somebody kindled a spark and there was life. **He came back to life.**
- He was like this empty shell. Even though he tried to keep this facade and this front up for people. And I think more for me than anybody. This put life... **This brought my (husband) back,** I mean, it was him again. It's hard to explain, but it was like from his toes all the way to the top of his head, he just filled.
- She was a lot **more of her old self,** like before her voice started going, she just was tryin' to joke around as much as she could.
- For the first time in a long time, **we got to be just ourselves,** and concentrate on one another, not my illness. You know, it didn't take the forefront anymore, and we just got to go out and have fun like we used to...

### **The dream experience took dreamers back to past times and passions.**

- It kinda **took me back 60 years,** and it just made me think about a lot of good things and times in my life.
- Seeing him there and having him in pictures and all dressed up, and you could tell **he was so proud to be in a suit.** And my dad always took pride in his appearance. So just seeing the pride on his face, of just how good looking he looked. It was just, it was so meaningful.

## Cognitive/Physical Health

### **Dreamers were able to set aside the physical limitations of their illness and feel normal.**

- They always come in the hospital room, because you're usually there at least a week or two weeks normally, and it's like, "Well, how are you feeling today?" Well, I'm feeling kind of isolated. **So doing something like this, it makes you feel normal.**
- We would keep my meds in a backpack, and make sure I had some kind of snack in case my blood sugar dropped. But it was a little more discreet, I guess you would say, because everybody was carrying around a backpack, and **you didn't feel like you were standing out because of it.**
- It kind of **made me feel normal again** to be out and about in that kind of situation. It made me feel more like my old self.

## Emotional/Psychosocial Health

### **Dreamers were apprehensive about whether they would be able to fully enjoy their dream experience.**

- Wanting to make sure that **I am going to be able to do everything** and make it enjoyable for my wife.
- There was this guy in the room behind the desk that I was sitting at, and he was hacking up a lung, and I'm like **"Please don't let me get sick before this trip."** It was the same thing at home. It was, like, don't anybody come over to this house if you've got anything.

- I couldn't wait. I couldn't sleep. It was hard for me to sleep because I kept saying, what if I'm sick and not feeling good. What if I'm too tired in the middle of a tour because you're gonna be doing a lot of walking. Matter of fact, that's the most walking I have done in a long time.

#### **The dreams provided something positive for dreamers to look forward to and look back on.**

- She was very excited about it. It really gave her a lot to look forward to.
- Dreamweaver gave me something to hope for and a pick me up, and I think everyone should have some type of hope or a dream or a pick me up during bad times. It doesn't have to mean you're dying, but any bad time, you need a pick me up. And they did that for me.
- Dreamweaver gave me something to keep that dream going because you need something to keep positive when times are gonna be hard. And I know that cancer never goes away. It's always there, it may be chronic illness later down the road, but it's always gonna be there. I needed this dream for something to keep me, my spirits going.

#### **The excitement of the dreams lasted over time.**

- I was on a high for probably the two weeks prior to the trip until ... months afterwards.
- He was like a kid in a candy store. It was reality, it's now gonna happen, they got plane tickets, we got our dates, we're booked, it's gonna happen, and that was when he finally let his guard down.
- He was out in the stadium for a little bit and there was just a genuine peace and calmness and exhilaration all at the same time. He kept looking around and seeing the grandkids there and me and my brother there. I don't know if he was thinking about mom. It was very emotional.
- She just kept jumpin' around like, "Wow, it'll be fun to go out like this." She got very excited and her spirits were up for quite a while.

#### **Both the dreamers and their families found happiness through the dreams.**

- It was nice to finally see her smile. It was nice to see her able to enjoy it.
- I said "Are you having fun?" and she's like "I'm having the best time." My mom is not one that really shows her emotion too much.
- I think she enjoyed seeing me so happy. You know, as she says, for the first time in a long time, sorry. I know that she enjoyed seeing me excited. It did make me feel much better to see her enjoying herself like she did, because I did have that tinge of guilt that I should've thought of something else that she would've enjoyed. But she did, she had a good time.
- She was very happy, because she so happens to like that genre of music also, but she was happy because I was happy. As a matter of fact, she (daughter) says, "Mama, I haven't seen you smile like this in a long time."

#### **The dreams provided a distraction from the burden of illness.**

- Her problem is a deteriorating back, and pain is a big issue with her. And normally, she's taking pain pills quite often. She spends most all of her time in bed. But we spent ... at least six hours away from home and except for probably the last hour, she was very distracted and really enjoying herself.
- I experienced the south, and I still think about it every day because it's kind of like my meditation. If all the Dreamerweavers came in my life basically to give me hope and get my mind off of the cancer.

- It was a **distraction away from the day-to-day things** that we needed to do and something that we just wanted to do.
- It really was a chance to get away from the daily grind of doctor's appointments. I still had to do all my medicine and keep an eye on things, but **you're just able to escape**.

#### **For some of the dreamers, the dream provided a sense of peace and closure.**

- She said, "I've done everything that I could." And she was very proud of all her children. And she said, "I just felt so happy tonight 'cause I was surrounded by love." And I think that's the reason why **she didn't have such a heavy heart, is because she knew what she was leaving behind was gonna be fine**.
- He was out in the stadium for a little bit and **there was just a genuine peace and calmness and exhilaration all at the same time**. He kept looking around and seeing the grandkids there and me and my brother there. I don't know if he was thinking about mom. It was very emotional.
- To have dad at a baseball game without mom being there, it was gonna be an emotional thing. **But it kind of was like completing a circle and trying to heal**.

### **Social Health/Relationships**

#### **Dreamers felt recognized and valued by their dream experience.**

- It made her feel very special. It was hard for her to understand why would somebody do that. It's just not a generation that you, people do that. But she just cried. The times that Ashley came over to give her different things, she just cried and **it made her feel very, very special. Like she was the most important person in the world**.
- **We felt like celebrities**, I kid you not. We walked into the restaurant and they knew us by name.
- When all the attention is on them, it just **makes them feel like a king for a day**.
- On so many different levels, it was all about her. The **experience was definitely focused and driven on her**.

#### **The dreams provided an opportunity to connect with loved ones.**

- I have a picture of when they were getting ready to leave, **my daughter in her wedding dress, leaning down and giving him a hug and a kiss**. That is just, it's priceless. It's just you can't put words to it, how meaningful it is.
- We'd never been to their place before, and so it was really neat. You know, **we got to see family, spend some time with them**, plus do all the race activities and everything.
- **We got to concentrate on each other, and just having a good time**. And you know, when you're in the same environment day in and day out, doing the same things, it's hard to do that.
- My sister-in-law, **she nominated me, and it was a good thing for both of us because we got to know each other**. And that was important. My brother and I were very, very close.
- **We as a family needed that to bond**. It enabled us to be happy that day and laugh and joke instead of cry and be miserable and enabled us to be happy for him and celebrate with him and he fed off of us.

## **Spiritual Health/Significance**

For some of the dreamers, the dreams carried with them a significance beyond the experience itself. Some saw it as a last chance or a once-in-a-lifetime opportunity, while others attached a spiritual significance.

### **Some of the dreams offered a once-in-a-lifetime opportunity.**

- It was just so relaxing, and we saw so many things. It was very interesting to see it, because otherwise we would never have seen that.
- It's just something that we never thought we'd be able to do.
- It was an amazing trip, right from the get-go. We've never been on anything like this in our life.

### **Other dreams provided a last chance experience to the dreamers.**

- We're all gonna leave this earth at some point and for him to be able to have done that and fulfill that dream, because of this organization. He would have left this earth and never fulfilled that dream.
- We knew we couldn't, we wouldn't go back again. So I'm glad we did go.
- It meant that I should really make sure that I enjoyed it and took advantage of it, because I know it's probably not gonna happen again.

### **The dream experiences provided a spiritual connection to some dreamers and families.**

- All through my life, through trials and tribulations, I've leaned on God. And I believe that angels are around us here and there. And when they come across to give me a dream, I thought, he gave me hope to do what I wanted to continue to do and that was to travel and see the world before I'm done.
- Only 25% of people that visit annually ever get to see the summit because of the cloud coverage. All of a sudden the clouds parted, and I said it was a God moment because... God truly had a hand in that for him to be able to see that summit.
- It was almost like mom (who has passed away) was here that day, and she was helping get us out the door and be happy that day.
- She never wanted to talk about leaving. And so to know that she had everybody around her, and if you look through the pictures, she's just holding on.

## **THE DREAM'S LEGACY**

The dream experiences produced intense emotional and social impacts on both the dreamers and their families. In some cases, the significance of the experience transcended verbal description.

## **Cognitive/Physical Health**

### **Dreamers reported being revitalized and motivated because of their dream experience.**

- When you haven't done a lot for a while, you need confidence and Dream Weavers gave me confidence.
- I told my wife as soon as I get home, I'm doing that in the garage, like I used to do.

- It just makes you want to, [makes me want to stay healthier longer](#), in case I get an opportunity to go do something, or make my own opportunity to go do something.
- [It just revitalizes you](#). When you're in a struggle or a battle with a terminal illness, just something like this can make such a difference.

## Emotional/Psychosocial Health

### **Dreamers and their families were offered hope through the dreams.**

- For a while, that experience lifted her. For a short amount of time, it was able to [lift her out of her funk](#).
- I think what it did, [it gave her a sense that life isn't over](#), because when you lose a spouse you don't have anything to look forward to. It's a day-to-day, day-in and day-out, the same thing over and over. Having something to smile about and reminisce about was really very important, it's very special.
- It [put a little zing in your step](#), as they say. I walked a little taller and just felt better about life.
- Other than they made me so happy to be able to [fulfill that void that I was having](#) that I thought I would never see again because that was always important to me, to travel.

## Social Health/Relationships

### **Some dreams provided opportunities to connect to new people.**

- We stayed with the relative of a friend, and [I still am in touch with them](#). We're Facebook friends and they actually moved back, they moved back to Nebraska.
- Dreamweavers gave us a chance to even [connect with our neighbor](#).

### **Powerful memories of loved ones were created through the dreams.**

- The new race coming up here in a couple weeks, I just kind of [reflecting and all these things are coming back to mind](#) that I haven't thought about for a few months. Oh yeah, I remember we did this.
- It was priceless, because I knew that this was the only wedding of a grandchild, that he was gonna be able to go to. So seeing him there and [having him in pictures and all dressed up and you know you could tell he was so proud to be in a suit](#).
- I do not have any pictures with me and my mom, and not since I was small, so it was [nice to be able to get some current pictures with her](#), and you could tell she was very happy to have those pictures 'cause she's got them sitting in her kitchen.
- It was nice to be able to have us, to be together, to be able to take pictures. In fact, I took some pictures during the game, and [I made a photo collage and had it framed for her](#). She has it sitting on her kitchen counter.
- [We made our \(photo album of the trip\)](#). And if you'd love to see it, we could bring it to you, or whatever, I mean, it's fantastic.
- It's good, because I talk about it, and I have told my out-of-town friends about it, and they just kind of couldn't believe it. But I do, I still think about it, and then of course [I have this portrait sitting right here beside me, that they took, that I look at every day](#).

- [I get that journal out as a reminder.](#) Because it's a happy time, it's a happy place, you know? It takes the sadness away. It gives me something nice to think about. I don't know if that makes sense. 'Cause it was a wonderful perfect time.
- When dad was again at the hospital and the doctor said, are you ready to turn off the oxygen, and all that stuff, and it was like all [I kept seeing in my mind were those images of him sitting there](#) and me watching him from behind how he was taking everything in, how he knew what was going on. It was such a beautiful, beautiful day.

### Spiritual Health/Significance

#### **Many of the dreamers and their families were humbled by and grateful for the dream.**

- [I'm just grateful.](#) You know, I don't deserve it. But it was incredible, and I wouldn't change it for the world. I'm so thankful for it.
- Wouldn't change it for the world. [Couldn't thank them enough.](#)
- What they [give people at that place and time in their lives...](#) That spark, just that glimmer of life.

#### **There were even dreamers who incorporated their dream into their final wishes.**

- So we had asked her and before she completely was no longer conscious, I said Mom, I said [do you wanna wear your outfit when you go to Heaven?](#) And she said, "Yeah. I felt like a princess. And don't forget my shoes." So I was like, "Oh my gosh, Mom, I won't forget your shoes."
- Do you want your ashes interned or do you want them sprinkled somewhere? He goes, "[I want my ashes sprinkled in Alaska,](#)" and I went perfect, then that's what we'll do.

#### **The dreams even moved some beyond words.**

- The way I describe it to everybody, the most amazing part of it was [to see the look on his face.](#)
- There are [no words for the amount of gratitude](#) that I have for Dreamweaver.
- [We don't have any words.](#) It's like what I tell people, we still talk about it today because we still talk about, we look at the pictures.

## **DREAMWEAVER FOUNDATION'S STRENGTHS AND CHALLENGES**

The interviews intentionally focused on the impact of the dreams on the dreamers and their families. While not asked specifically to evaluate their experience with the Dreamweaver Foundation, the interviewees were quick to share thoughts about their dream process. That input translated into some powerful strengths and potential challenges for the Foundation.

### Strengths

#### **The caring staff of the Dreamweaver Foundation were identified as its greatest strength.**

- They're a step above, especially in how they handled our situation. With just such love and such enthusiasm. Oh my gosh, I was just like, Cheri can I have some of your enthusiasm? I could really use that right about now. And you could just tell that [she's just passionate about what she](#)

does. And she probably makes everybody's life better that she touches. I know that she definitely made our life better...

- You could tell that **they're invested**. **It's not just a job, it's a calling**. You know what I'm saying? And we were very much, I was very much impacted by that, and just by the, the **generosity and the genuine spirit** at which things were accomplished and done. You could just tell that this was, they cared deeply and embraced what they do, on such a personal level.
- Ashley, she's my angel. But it takes a **special person and an angel to make you feel important and still worth living**.
- We were treated so nice, and like I said, **she calls a lot of times to see if we're alright**, and if she can do that, and if we need anything, so that means a lot to us. Because nobody does that.
- Ashley was a great, great, great representative of the organization, because she did not have any, there were no barriers, **there were no walls that my mom ever felt with her**.
- I was finding it really hard to try and be happy with dad but Ashley took that role. **I felt like with her she lead the way, and she took care of everything**. It was kind of like, "Don't worry about being happy or sad for him I'm taking care of this. You just follow as you need to."

#### **Dreamers and their families felt a strong connection with Dreamweaver Foundation staff.**

- **Cheri came and spent time with my mom and dad and, got to know my mom and dad. And even made a connection**. She sings, my dad sings, so they talked about that. You know what I'm saying? Just made a real connection there.
- Things like this wouldn't have happened if Dreamweaver, specifically Cheri Mastny, because to me **I mean we have a connection that will be there for the rest of my life**.
- Just to see my dad and when Ashley would come in, it was like **she was definitely part of the family**. She still is we still consider her but really more so in that journey because they came at just the right time.

#### **The dreams were responsive to the input and needs of the dreamers and their families.**

- **I know in my heart, I don't think we would've been able to do anything like what Ashley did, what her organization did**. Because there's just, **there were too many details that she thought of for us**. And so it took that weight off of us.
- They came over and they talked to me, and just kind of asked what we would like to do, or what we knew about the Daytona 500. **They definitely took my input, they just ran with it**. I mean, and boy, did they run.
- It was just, **it was a great day that I couldn't have pulled off by myself**, as an individual. The fact that they were able to get four tickets. To manage somebody in a wheelchair, with parking, and that kind of thing is difficult. Bathroom breaks, that kind of thing, but to have that extra person or two people, it was just wonderful.

#### **The dreams exceeded expectations.**

- They went so over, you know, **above and beyond what I expected**. It was just, it really was phenomenal.
- So it never in a million years did I think there was something like that for old farts like me, and you know, like I say, **they just went so over the top with everything they did for us**. I'm still in awe of it.

- It is quite another thing to have an [organization step in and just literally take this responsibility from you and run with it](#). It's not like I was having to orchestrate what they were doing. They just took it and ran with it. And did it to beyond perfection. And handled every last little detail. And it was just amazing. I mean I felt humbled. And it's like good grief they just like, took it from me, which was exactly what I needed someone to do.
- No way, [I don't think there was anything more they could have done](#).

#### **The dreamers and their families felt a desire to reciprocate.**

- [If had a million dollars, I'd give it to them to let other people live out their dreams](#). But yeah, it was incredible, and I am so grateful for it.
- When the trip was over and there was still about \$200 left on the card, and she said, well, that was meant for you guys, why don't you just buy groceries, or buy gas, or whatever? And I said, you know, we don't feel that way, [we'd rather give that money back, and maybe put it towards the next dreamer](#).
- [I would do anything for her and anything for that organization to thank them](#). I have never been able to thank them in the way that I think they need to be thanked. I know they don't feel that like they need to be thanked in any special way.
- I would love to do more for the Dream Weavers. Give people more hope. That's why I asked Ashley for those [brochures](#). [I pass them out to the social workers](#) because who better knows these people who are sick and knows their financial issues than the social workers, the pastors, the priests. So that's where I sent my information to. And friends and family that are going through cancer, and say here, give them a dream. And if I can continue to do that, I'm gonna do it.

#### **Referral sources were most often service providers.**

- So we were [working at senior center](#) before, and that's how you kind of connected with Dream Weaver.
- [We have recommended a couple different people](#). We've recommended a person who lives right across the street.
- We [worked with Eastern Nebraska Office of Aging and our social worker](#). And she would do monthly visits and she said, "I had a visit from an organization that likes to grant wishes to senior citizens."
- We went on hospice at that time. I guess [one of the ladies from hospice](#) contacted Dream Weaver.

### **Challenges**

#### **Dreamers and their families were skeptical of the dream offer.**

- [We just thought well, "That's probably a joke,"](#) and we just kind of blew it off, you know?
- When the [social worker](#) told me, and even she [was kinda skeptical](#). She was like, "I'm not quite sure what they do."
- Dreamweaver is not some fly-by-night or some company that's gonna try to take advantage of us. You know, get our account information or just all the bad things that happened that you



hear in the news because we didn't know this organization from Adam. And they instill in you, if it's too good to be true, it probably is.

- My daughter actually heard a commercial. It was radio or TV about this organization called Dreamweaver and it was, like, Make a Wish for seniors.

#### **Scheduling the dream can be a challenge with the progression of a terminal illness.**

- Scheduling the dream would have to be according to what condition I was in.
- She's getting weaker, and I just don't think she can handle the trip. And at that point, I was just ready to say thank you, I appreciate the offer. And it was Ashley who said, "Well, we're still gonna do something for her." She said, "I still wanna grant her a wish."

#### **It is important to position the program as a "life-long" dream rather than a "life-end" dream.**

- The gal introduced us to the three drivers in the trailer and explained that I was there "...as part of the Dreamweaver Foundation. We partner with them. They work with people 55 and older who, well, um, "won't be with us much longer." It's, well, nobody told me that.  
vs.
- It was a nice way that Ashley approached it. It was never, "What's your last wish?" It's, "What have you always dreamed of doing? What's your dream?" And that's how she always asked my mom. And so it was always about, "What do you want, what's your dream, what's your wish?" Never once did I hear her imply last, or dying, which is great because I don't think my mom would've wanted it if it was always implied, this is your last, this is your dying wish, or this is your last hurrah. I don't think she would've wanted anything like that.

## **CONCLUSION**

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Dreamweaver Foundation is making a difference in the lives of terminally ill seniors in need and their families. These interview findings provide evidence that the Foundation's work is playing a role in the quality of their lives. Along with the medical care professionals addressing their physical and cognitive health, the palliative work of the Dreamweaver Foundation fits into enhancing the identity, emotional, social, and spiritual health of its clients. One dreamer explained that niche by saying:

Because that's the thing about cancer. Doctors and nurses are terrific in radiology and all that, they're fantastic. And they're there when you need them. But they can only do so much. And that's when you gotta be strong and that's when you gotta be positive. And if somebody like the Dreamweaver Foundation comes along in my life to say I'm here to give you a dream. That makes you happy because it gives you something to look forward to.

In particular, these dreams provide a revitalization and re-connection for dreamers along with a reprieve and positive memories for family members. One family member summed it up by saying:

They entered in a very deep black hole and they just kind of took our hand and said "We're gonna walk this road with you." For a little while, there was just an incredible kind of peace.

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