**Interviewee: Mizzy**

**Interview Date: Tue, 03 Aug 2021 12:35:20 GMT**

**Company: Caregiver**

**Notes:**

**Question: What were the challenges with the current health care system which affected the treatment process positively or negatively**  
  
My mom's cancer Dr was very rude. His first words to us was you have 3 months to live, Then he sent in only 2 months of short term disability and told her primary care Dr she should have been dead so I made him send in her last payment he also refused to do a bloodwork panel on her .. her potassium levels was so low she almost died of a heart attack  
  
  
**Question: How did you deal with all of this?**  
  
No I filed a complaint against him with the board and found my mom a new cancer Dr

**Question: Whom did you reach out to for help?**  
  
I was so stressed a mad I had to call my husband to vent  
I called cancer center of America sometimes for help and advice

**Question: Why do you vent?**  
Yes, cancer center or social groups. All help me vent.  
if I didn't get it off my chest I probably would have punched that doctor in his face  
  
Well I never vented a lot on social media. Too many people on fb judge you so that is why i don't vent on fb  
  
**Question: Do you find social groups useful for venting?**  
Response: I would have to say everyone has different views of life and people need to be more open on other people views  
  
**Question: How did you finance the treatment?**  
  
My mom had good health insurance she worked 47 years for the same company and the owner of the company help pay for her medical bills that wasn't covered because she was the only reason he could retire

**Insights:**

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| --- | --- | --- | --- |
| **Quote** | **Comment** | **User** | **Finding Type** |
| My mom's cancer Dr was very rude. His first words to us was you have 3 months to liv |  | Pratha Mandwal | General Insight |
| My mom had good health insurance she worked 47 years for the same company and the owner of the company help pay for her medical bills that wasn't covered because she was the only reason he could retire |  | Pratha Mandwal | General Insight |
| Yes, cancer center or social groups. All help me vent. |  | Pratha Mandwal | General Insight |

**Interviewee: Dr Ruhi**

**Interview Date: Tue, 03 Aug 2021 11:04:26 GMT**

**Company: Skin doctor and wellness**

**Notes:**

**Question: How did you recognise your cancer?**  
  
During the covid, and with my cancer. One thing is very clear to me. The ones who are destined to survive, will survive.  
I was admitted to the hospital because I had a brain tumour and heomerrage cyst. But doctor suggested me to get checked for biopsy.   
I had no idea about any lump, and suddenly i had cancer    
  
**Question: How did you deal with the diagnosis?**  
  
My life changed with the diagnosis. I kept thinking, my dreams were totally different. It was my daughter's birthday party, we were planing. Then suddenly i had cancer. I felt, my life's going to be changed. But still i was optimistic  
  
But then, when i told my family, every one were so stressed. That's when i realized that a very bad thing has happened.  
  
**Question: How did you deal with Masectomy?**  
  
When masectomy happened, at first i thought that my body part is removed. But then i consoled myself.   
  
My husband and my mother in law supported me alot.  
for my entire treatment, i thought, i have to go through with it. My target was focussed, on my daughter. I thought, its for her, i need to recover.   
  
**Question: What was the most difficult part of the entire treatmnet?**  
  
Taking the most difficult life alterting decisions. Once during covid, i developed lung infection due to mishandling off the cancer pot. I was burning with fever almost 105-106 by then. My oncologist knew i had no covid. But due to ongoing covid, the hospital was keen on shifting me to the covid ward.   
Shifting my hospital was unavoidable due to criticality of my condition.   
There was lot of conflict, my family was not agreeing on one decision.  
  
  
**Question: Who helped your family reach a decision?**  
  
There is no helpline or guideline. We have an oncologist in our relation. He helped us take a decision.  
  
**Question: Did social media help you in taking your decision?**  
  
Social media came to my notice at much later point, when i joined the sangini app.   
  
  
**Question: How has your experience been with whatsapp group?**  
  
I like that one can learn about the process using one's friend circle. You can get mental support, learn about the process. day-to-day pain points.   
When some says 'humko bhi hota tha' its a very relaxing thing.   
I think when there are not many choices left, there is just one option. 'To Be happy'.   
  
But group has negative things also. Suppose there are 20 people in the group, out of this if 15 people have relapse, then remaining 5 will be very scared. This creates negativity.   
  
**Question: What would be your advise to other patients?**  
  
The patients who are newly diagnosed must look at patients who have recovered. They should envision that they are recovering like these patients  
  
Question: What other practical solutions that you can think of?   
  
One of my fried suggested me games to engage. In first week, i used to write all the great things that happened in my life. In another activity, i used to think of all the things i want to achieve  
  
Meditation helped me alot. I particularly like Yog Nidra, because they direct organ by organ to relax.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| When masectomy happened, at first i thought that my body part is removed. But then i consoled myself. |  | Pratha Mandwal | General Insight |
| for my entire treatment, i thought, i have to go through with it. My target was focussed, on my daughter. I thought, its for her, i need to recover. |  | Pratha Mandwal | General Insight |
| My life changed with the diagnosis. I kept thinking, my dreams were totally different. It was my daughter's birthday party, we were planing. Then suddenly i had cancer. I felt, my life's going to be changed. But still i was optimistic |  | Pratha Mandwal | General Insight |
| Meditation helped me alot. I particularly like Yog Nidra, because they direct organ by organ to relax. |  | Pratha Mandwal | General Insight |
| There is no helpline or guideline. We have an oncologist in our relation. He helped us take a decision. |  | Pratha Mandwal | General Insight |
| Once during covid, i developed lung infection due to mishandling off the cancer pot. I was burning with fever almost 105-106 by then. My oncologist knew i had no covid. But due to ongoing covid, the hospital was keen on shifting me to the covid ward. | Not sure how to address it | Pratha Mandwal | Feedback |
| The patients who are newly diagnosed must look at patients who have recovered. They should envision that they are recovering like these patients |  | Pratha Mandwal | General Insight |
| But group has negative things also. Suppose there are 20 people in the group, out of this if 15 people have relapse, then remaining 5 will be very scared. This creates negativity. |  | Pratha Mandwal | General Insight |
| When some says 'humko bhi hota tha' its a very relaxing thing. |  | Pratha Mandwal | General Insight |
| One of my fried suggested me games to engage. In first week, i used to write all the great things that happened in my life. In another activity, i used to think of all the things i want to achieve |  | Pratha Mandwal | General Insight |
| I had no idea about any lump, and suddenly i had cancer |  | Pratha Mandwal | General Insight |

**Transcript:**

**Interviewee: Lucy**

**Interview Date: Fri, 07 Jan 2022 23:35:37 GMT**

**Notes:**

**Q: How different is it from hosting cancer patients or other patients who travel for sickness or medical treatment?**

It's not. I don't believe we have hosted a lot of patients we live pretty close to Children's Hospital. And so, we have had cancer patients stay with us and they like it. I mean, I guess it's part of our house. We are still living like we're breathing the same air through the vents, as far as like an immunocompromised person just considerations. But I think it's the same in hotels. So, I'm not really sure how it's different.

**Q: What are rewards of hosting your house on Airbnb?**

The rewards would be financial. Having income to pay my bills, my mortgage and work on my house 100 years old. Also, it's feels nice to help other travelers. I have done a lot of traveling and I almost always choose to stay in an Airbnb over a hotel. Because I find that much more comfortable and I also like having a kitchen. It's also a space in my house that we're not really using. It's our basement. And my sister and her husband used to live there and then we had a roommate live there. And then we just thought, let's try Airbnb. And so, we did that for a few years. For short-term stays, and then with the pandemic spring of 2020, we switched to long-term stays. So now we do a minimum of 28 nights, and we make way more money and do far less work and it's a way better situation for us.

**Q: What impact do you see in charging less like, how does it How much do you think it will affect the hosts willingness to host on our platform?**

I think rentals are very expensive. And the pandemic least as a short-term rental host I know a lot of hosts chose to stop putting their space during the pandemic. And like we were empty, we had a long term stay person with us, and they ended up leaving because of the pandemic and then we were empty for like six weeks. And so, like that definitely impacted posts, because then people were not really looking for accommodations. But yeah, rentals are really expensive in Seattle, and it's pretty hard to find a furnished rental. So that's definitely another difference. With Airbnb, you just show up with your clothes and everything else is already there. You don't have to travel with much. I have not experienced cancer patient asking me to charge less because they're a cancer patient.

**Q: What kind of amenities you might want to add to make your stay more convenient for a patient?**

Yes. We have a kitchenette. So, there's not a stove or an oven. So that is an amenity that we could add. We do not have Driveway parking for people but street parking is free and always available in our neighborhood now we get really good reviews.

**Q: Do you think the distance from the hospital is a pretty important parameter for patients stay when they travel to another location for treatment?**

Yes, I have been told by our guests that one of the reasons why they picked us and why they chose to stay with us for so long was because of the proximity to the hospital.

**Q: What challenges you see you think that patients experience when they travel for treatment?**

I would say housing is a significant challenge and cleanliness, having a place that is clean. Trust is a big one just not knowing who you know if you're saying in someone else's house, it's kind of a freaky concept. Like can you trust that they're not gonna walk in our house when they have a key? Or that there's not like a camera I think not knowing the length of stay is one of the most significant considerations for patients. Because, you know, even if they're told their cancer treatment is only going to be five days. There are often significant complications and so length of stay often get drastically extended. And it's very touching those situations where if you're hospitalized every day is a different situation. So, it just depends on what their what their blood counts are doing, how much transfusions they need, or do they have an infection, how stable they are, are they able to leave? So that's probably one of the biggest ones is it's really hard to play on.

That's a problem like an Airbnb host or hotels is not just going to be sitting around waiting. If somebody books with me for five days there, they have to leave the day that they're checking out because someone else is coming the next day. It would be a challenge as a host and as a patient. For example, if somebody have booked for five days, and that means that the sixth day if I have if I don't have it blocked on my calendar, then somebody else can check in the sixth day. So if you know the cancer patient has been with me those five days and they call me on that fifth day and they say they have to extend their stay. It’s challenging that my options as a host are either to cancel the person who's checking in that next day, or to let this patient book another time, not this time. It reflects poorly on hosts to cancel and then that's really disruptive to the incoming person who might also be a cancer patient.

**Q: As you mentioned, patients care about being able to establish trust with the place that they're traveling. So how important it is for the patient to be able to trust the host given that they are in their vulnerable times?**

Personally, tend to not worry about things like that that much like. As a guest as an Airbnb user myself, you read the reviews of the other people that have stayed there. You might look into the host a little bit yourself. So, we have a profile on Airbnb, it says I'm a nurse and my husband is a carpenter. And we have good reviews. So, we have established credibility. Now if I wrote that I'm a businessperson, or to exploit cancer patients, then I don't think we would get customers, so I think a lot of it's just how you present yourself and then how you're received by your clients.

**Q: What’s your view on micro-donations as a donor? For example, some donor pays $10, and we will be charging $2 for ourselves as a platform?**

It makes sense that a business would require money. So, I think as long as you're transparent about what where their payment is going, and where that $2 goes. I think it would be fine. I don't personally donate to any housing causes right now. So, I would probably not participate in that personally.

**Q: What kind of challenges do you think that convincing people to this cause we might face?**

I would say financial and then finding the people that are passionate about helping people with cancer. I think people that want to help people with cancer will be interested. I donate to other causes. There are a lot of people that do want to contribute to this cause. So, I think it's just finding who those people are and getting them getting their buy in. I think it's a really great cause and it's a really significant problem.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| It’s challenging that my options as a host are either to cancel the person who's checking in that next day, or to let this patient book another time, not this time. It reflects poorly on hosts to cancel and then that's really disruptive to the incoming person who might also be a cancer patient. |  | Veronica Gu | General Insight |

**Transcript:**

**Interviewee: Trapti Golash**

**Interview Date: Tue, 03 Aug 2021 08:02:19 GMT**

**Notes:**

**Question**: **How did you realize you have cancer?**  
  
few days back, around march, I felt a lump in my chest. I am from khandwa. I felt suspicious. So, I went to get a mammography.   
  
  
  
Doctor recommended Biopsy. I had breast cancer.  The doctor operated on it to remove the cancerous cells.  
I went through 6 cycles of chemo. Since, my cancer was diagnosed at the first stage, it was straightforward  
  
  
  
**Question: How did you deal with the shock?**  
  
I am a yoga teacher, due to the diagnosis, I don't practice extensively anymore. I have a boarding in front of my house, which says, cancer makes you disease free. I am pretty scared about how this diagnosis is going to affect my profession.  
Due to the chemos, my hairs are falling, which saddens me.   
  
There is lot of pressure from the society. I have not told anyone.  
  
  
**Question: Why haven't you told anyone?**  
  
Because it will affect my profession in very negative ways  
  
**Question: Did you ever doubt, that you might have cancer?**  
  
Response: I don't have one fallopian tube, and one ovary. During my second delivery, there were multiple issues. So, I always suspected something could be off with me. But even in my worst thought, i did not think i will have cancer.   
  
**Question: How are you coping with cancer?**  
Response: Entire game is about "Will power". I was very scared about the effects of the chemo. But, yoga, tea and naturopathy has affected me positively.  
  
My family supported me a lot. Because of  
Meditation, art of living and brahmakumari , I am able to survive.  
  
I am counting on hope and luck  
  
  
**Question: How do you seek the guidance that you need?**  
Response: Doctors are very helpful, sangini whatsapp group has helped me a lot. But, I seek counsel only from doctor.   
Traditionally people say, eat papaya that will help you. Try ayurvedic medicines etc. But, I prefer to avoid all this. Every thing has side effects that will affect the way your treatment has been ongoing.   
  
**Question: How are your family members affected by your diagnosis?**  
Response: I try to prevent the intensity with which my family is affected.  
  
  
**Question: How do you handle the nutrition?**  
Response: Most recently my sugar shot up, because of eating lot of fruits. I am actually a fruit lover.   
but actually sugar really spikes up your sugar.   
I keep in coordination with the dietician. She has recommended me to have nariyal pani, dry fruit etc.  
  
**Question: What about your love for yoga now?**  
Response: Doctor has asked me to try physiotherapy. The physiotherapist has taught me to basic asanas.   
The trainer charges around 400/day, He conducts a 40 min online session.  
  
**Question: How did social media help you in your journey?**  
Response: These days, I am free a lot. I feel very restless. Sangini group made me believe that I am not alone.    
  
**Question: How about fb?**  
Response: I didnot refer facebook groups for alternate solution, mostly because i had already made up my mind about chemo

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| Meditation, art of living and brahmakumari , I am able to survive. |  | Pratha Mandwal | New Hypothesis |
| Most recently my sugar shot up, because of eating lot of fruits. I am actually a fruit lover.  but actually sugar really spikes up your sugar. |  | Pratha Mandwal | General Insight |
| The trainer charges around 400/day, He conducts a 40 min online session. |  | Pratha Mandwal | General Insight |
| Because it will affect my profession in very negative ways |  | Pratha Mandwal | General Insight |
| There is lot of pressure from the society. I have not told anyone. |  | Pratha Mandwal | General Insight |
| I didnot refer facebook groups for alternate solution, mostly because i had already made up my mind about chemo |  | Pratha Mandwal | General Insight |
| There is lot of pressure from the society. I have not told anyone. |  | Pratha Mandwal | General Insight |
| I am a yoga teacher, due to the diagnosis, I don't practice extensively anymore. I have a boarding in front of my house, which says, cancer makes you disease free. I am pretty scared about how this diagnosis is going to affect my profession. Due to the chemos, my hairs are falling, which saddens me. |  | Pratha Mandwal | General Insight |
| Response: Doctors are very helpful, sangini whatsapp group has helped me a lot. But, I seek counsel only from doctor. |  | Pratha Mandwal | General Insight |
| These days, I am free a lot. I feel very restless. Sangini group made me believe that I am not alone |  | Pratha Mandwal | General Insight |

**Transcript:**

**Interviewee: Dr Yogeshwar Shukla**

**Interview Date: Tue, 03 Aug 2021 08:14:07 GMT**

**Company: Oncologist**

**Notes:**

Interviewee :  
Dr Yogeshwar Shukla  
Doctor, Oncologist  
  
  
  
Question: How do you interact with the caregiver?  
Response: We prefer that the patient never comes alone, that’s because when we tell the patient such  
bad news, the patient goes into a traumatic state of shock. He goes through a loss of understanding. We  
prefer to start communicating with the caregiver, because we can make them understand the details of  
the treatment.  
  
  
Question: What role does the caregiver play in the medical treatment process?  
Response: Caregivers motivate the patients, without the caregiver, I have noticed that there are greater  
chances of patients dropping out of the treatment.  
They are also more informative than the patient.  
  
  
Question: Is it easy/hard to coordinate with the caregiver? Why so?  
Response: The biggest problem in my opinion is misinformation. Due to social media, a lot of  
misinformation is being circulated all around. There are a lot of patients who just come to us to find out  
their options. They don’t even have real knowledge.  
  
  
Question: What makes a caregiver unproductive? Why?  
Response: Apart from the misinformation, I think it's the belief that there is a magical solution. We cannot  
take guarantee. Alternative therapies, or sometimes religious gods will promote guarantees, misleading  
people.  
  
  
Question: Can you share with me about a time when a caregiver was facing a personal crisis?  
Could you help him? Why/ Why not?  
Response: Once, I noticed that the caregiver was undergoing clinical depression. I recommended that he  
go to the counselor. He didn’t pursue the idea. Instead he went to a general medicine doctor to take  
generic medicine.  
So, no I couldn’t help him  
  
  
Question: Why do you think the caregiver prefers general medicine?  
Response: The problem could be financial. The caregiver is somehow managing the expense of the  
treatment.  
There is also a lack of dedicated counselors, who counsel not the patient, but the caregiver. So, the  
caregiver finally has solutions to find a private counselor which is a very costly affair.  
  
  
Question: In government funded hospitals like Tata Memorial Hospital, It's hard to understand  
how there is a lack of counselors?  
Response: The problem with TMH is that the number of patients is humongous. The number is just too  
huge. They cannot cater to all patients.  
Then, there is always a stigma associated with psychiatrists,especially in uneducated folks. So, Rather  
than going to a psychiatrist , they prefer general medicine because of the stigma.  
  
  
Question: Given these problems, do you see any practical solution that can fix this?  
Response:Theoretically, I can say a lot of things like NGO needs to reach out more proactively, or  
government to invest more money. But most practically, I think, Doctors need to step up. They need to  
invest more on the patient to mentally prepare the caregiver about what’s going to happen now? How will  
your life change?  
Sometimes, the doctor assumes that because the patient is poor, he would provide them cheaper options.  
Take for example, a patient has breast cancer - I give all the financial options. Psychologically - any  
female doesn’t want to get breast removal . People are ready to shell out extra money if someone  
explains to them the need for it Communication part is lacking today.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| Theoretically, I can say a lot of things like NGO needs to reach out more proactively, or government to invest more money. But most practically, I think, Doctors need to step up. They need to invest more on the patient to mentally prepare the caregiver about what’s going to happen now? How will your life change? |  | Pratha Mandwal | General Insight |
| the patient goes into a traumatic state of shock. | After Diagnosis Shock | Pratha Mandwal | New Hypothesis |
| Once, I noticed that the caregiver was undergoing clinical depression. I recommended that he go to the counselor. He didn’t pursue the idea. Instead he went to a general medicine doctor to take generic medicine. |  | Pratha Mandwal | General Insight |
| Apart from the misinformation, I think it's the belief that there is a magical solution. We cannot take guarantee. Alternative therapies, or sometimes religious gods will promote guarantees, misleading people. |  | Pratha Mandwal | General Insight |
| Due to social media, a lot of misinformation is being circulated all around. |  | Pratha Mandwal | General Insight |
| he problem with TMH is that the number of patients is humongous. The number is just too huge. They cannot cater to all patients. |  | Pratha Mandwal | General Insight |

**Transcript:**

**Interviewee: Nupur**

**Interview Date: Tue, 03 Aug 2021 14:34:43 GMT**

**Company: family caregiver**

**Notes:**

**Question: How was the diagnosis process?**  
  
Response: Mummy papa went to Tata Memorial hospital for treatment. There were so many patients, it was so crowded.   
  
We have to keep waiting in line to get appointments.  
  
Though mummy had stage-1 cancer, cancer care doesn't change according to the stage.  
In the TMH, there is no specific doctor being assigned to you. There is a panel of doctors who decides the best course of action for you. so you don't even have a point of contact that can guide in day-to-day activities.  
 There is so much crowd, that even the operation was planned one month after the date that we had arrived.  
  
  
 Question: Which tool did you use to manage the treatment?   
  
 Response: The hospital had provided us a website. whenever the report is available, it is updated on that website. We used to keep checking it.   
 It used to take 4-5 days to get the report. We had to stay in a different city for a long time to manage the treatment.  
  
 Question: What happens after the operation?   
  
 Response: Evey 6 months, we need to get the check-up done. During the course of the operation, we were hoping that there is no chemo. But the side in which the operation has been done, that side is prone to infection.  
  
Before release from the hospital, there was a session conducted by the hospital to reduce the risk of mental depression. Technique to exercise.   
  
Question: How did you manage work with caregiving?   
  
Response: I had informed my manager about the medical emergency. I was able to take a break for few days. I used to mostly take her to the hospital first, then return back and complete my work.  
Sometimes, I had rescheduled work meetings or plan my day according to the treatment schedule.   
The main worry that I had was that the operation should happen properly.  
Mummy used to feel very irritated, I used to try to maintain my empathy  
  
**Question: Which was the most difficult part of the process?**  
  
Response: Perhaps, the most difficult thing was to keep my own peace of mind. To convince me that everything will be alright.  
  
**Question: What helped you overcome this?**  
  
Response: Very rarely do people actually care about helping you. Most of the time it's about gossip. We didn't want to involve many people at that time. I used to take help from my close friends and Sudarshana.  
  
**Question: Were social groups useful?**  
  
Response: In a cancer-specific social group, a lot of people are discussing cancer, and how it affected them. I try to avoid so much noise. I try to keep myself positive because that was the most important thing at that point.   
  
  
  
**Questions: When did you finally feel relaxed?**  
  
Response: In our rented accommodation near the hospital, there was no space to live comfortably. I was comfortable whence I moved to Bangalore for the radiation.   
  
  
**Question: How did you fund the treatment?**  
  
Response: We had our own savings.   
  
**Question: What can be done to make the treatment experience better?**  
  
Response: There is a shortage of hospitals, due to which there is so much crowd in these hospitals. The hospitals are not able to scale.  
Even the simplest of things like getting the date for the operation, or getting the report, took a lot of time due to the scale.  
  
  
**Question: How did you manage the nutrition?**  
  
Response: The hospital had given us a booklet which contained a lot of information about nutrition, course of exercise.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| he hospital had provided us a website. whenever the report is available, it is updated on that website. We used to keep checking it.   It used to take 4-5 days to get the report. We had to stay in a different city for a long time to manage the treatment. |  | Pratha Mandwal | General Insight |
| : In a cancer-specific social group, a lot of people are discussing cancer, and how it affected them. I try to avoid so much noise. I try to keep myself positive because that was the most important thing at that point. |  | Pratha Mandwal | General Insight |
| I was able to take a break for few days. I used to mostly take her to the hospital first, then return back and complete my work. Sometimes, I had rescheduled work meetings or plan my day according to the treatment schedule.  The main worry that I had was that the operation should happen properly. |  | Pratha Mandwal | General Insight |

**Transcript:**

**Interviewee: Mukesh**

**Interview Date: Tue, 03 Aug 2021 12:23:54 GMT**

**Company: Caregiver**

**Notes:**

**Question: What are activities you involve in day to day basis**  
  
There are a lot of tasks. and you can’t be at multiple places logistically.  
You spend most of your time in the hospital running from one counter to another. You need to be fit and  
hygienic.  
If you’re residing in a city, where there is no dedicated facility, then you might even need to move to a new city where treatment is available.  
  
  
Cancer patients are very low immune. You can't feed them random foods. You need to be very careful.  
Arranging Food for the patient, for yourself is another important task in my day.  
You need to arrange funds, you can’t leave patients anywhere. There is basically no time for rest, and for  
yourself.  
  
  
**Question: What special assistance do caregivers need?**  
  
Response: Sometimes, I feel I need little angels to help me with random events that make the day  
extremely challenging. On a very rainy day, if the roads are flooded, and I have to make it to the  
appointment, then it becomes extremely difficult if the patient is immobilized.  
  
  
**Question: How can such assistance be given to the caregiver?**  
  
Some initiatives are being taken which are pretty useful. For example, free food for the patient  
and caregiver. Or the various NGO trying to help the patient when they get overwhelmed. They try to sort  
out the medical treatment process for them.  
  
  
**Question:What’s the most difficult part of the entire medical treatment process?**  
  
You cannot leave the patient for 2 min, even when you actually need to arrange a lot of time  
critical things in real time.  
So the only solution remains to leave the patient on the wheelchair and then keep dragging it, which is by  
the way physically very consuming.  
You look for whatever comes to you, and you do. There is not much choice to it. This affects you  
professionally, physically and mentally.  
  
  
**Did you get any time off during the treatment process?**  
  
Response: You don’t get any time to sleep. Even when you try, rest doesn’t come very easily to you. The  
treatment process continued for 2 years, I remember using a urinary catheter when I had a massive  
health issue during the treatment. There was barely any time off.  
  
  
**Question: What’s your view on counselors?**  
  
Well they help you build your mental strength. But they are very difficult to scale.  
  
  
**Question: Given that you so desperately needed respite, why didn’t you consider leaving your**  
**patient to a professional for some time?**  
  
You cannot just leave the patient at random places. Patient feels confident when you are  
there with them. If the patient is a child then leaving is not even an option. Mobile phones have improved a lot of things.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| If you’re residing in a city, where there is no dedicated facility, then you might even need to move to a new city where treatment is available. | Moving to a new city will create challenges related to new locality , loss of work, increased expense | Pratha Mandwal | New Hypothesis |
| build your mental strength | What are other views to boost your mental strength which do not have stigma around it? | Pratha Mandwal | New Question |
| rest doesn’t come very easily to you. | Survey questions: What sort of solutions have been adopted to relax/ rest/ engage? | Pratha Mandwal | New Question |
| Sometimes, I feel I need little angels to help me with random events that make the day extremely challenging | if we connect cancer patients in a locality, they will help each other | Pratha Mandwal | New Hypothesis |
| You cannot leave the patient for 2 min, even when you actually need to arrange a lot of time critical things in real time. |  | Pratha Mandwal | General Insight |
| Patient feels confident when you are there with them. If the patient is a child then leaving is not even an option | Are caregiver comfortable leaving patient with another cancer patient ? | Pratha Mandwal | New Question |
| You need to arrange funds, you can’t leave patients anywhere. | Could reducing the effort to generate fund, generate food help patient and caregiver? | Pratha Mandwal | New Question |

**Transcript:**

**Interviewee: Bindu Mam**

**Interview Date: Tue, 03 Aug 2021 09:23:14 GMT**

**Company: highly spiritual**

**Notes:**

**Question: How did you get to know about the cancer?**  
  
Response: I was very lone during the entire process. When i felt i had lump, i went to the gynaec alone. The gynaec asked me to get mammogram, so then i went through it.   
  
**Question: How were you feeling after the diagnosis**  
  
Response: I just thought to myself, i am not going to cry. I will manage everything myself. I just left everything to god  
  
My husband decided to not sponsor my treatment. I was lost. My sister's husband used to take me for radiation.  
  
  
**Question: What was the most difficult part of the process?**  
  
Response: The treatment is very painful. Everytime during the radiation, there used to some issue or the other. I had around 28 seating. The rays were so heavy that i used to get injury.  
everytime there used to be shortage of platelets.   
I used to try very hard to maintain positivity.   
  
**Question: You were mentioning, you had no insurance, neither did your husband sponsor you. How did you manage?**  
  
Response: I used my savings, friends and family were also kind to help me  
when my surgery happened in gurgaon, my sister gave me her house for around 15-20 days. She kept me with her.  
Everyone's life is tough.   
  
**Question: What helped you?**  
  
Response: Meditation and spirituality. I have bee involved with the sangini group since a month. However, i don't want to involve much. I don't want to crowd my mind with useless information.  
  
**Question: Did you have difficulty managing your appointment?**  
  
Response: Planning for my appointment was my only responsibility those days. I didnt have any issues. My sister used to take me to appointments and plan accordingly.   
  
I think if someone is taking treatment from multiple hospitals, then they might encounter such issue,   
  
**Question: How can the medical system be improved?**  
  
Response: . I remember the crowd in front of the insurance counters, it used to take so much time to get the clearance from the company. Behavioral arguments were quite common.  
There are so many patients, even in elite hospitals like mine. There was not even place to stand.   
  
  
The doctors were so busy all the time. My doctor had even blocked me on whatsapp.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| The treatment is very painful. Everytime during the radiation, there used to some issue or the other. I had around 28 seating. The rays were so heavy that i used to get injury. |  | Pratha Mandwal | General Insight |
| However, i don't want to involve much. I don't want to crowd my mind with useless information. |  | Pratha Mandwal | General Insight |
| I remember the crowd in front of the insurance counters, it used to take so much time to get the clearance from the company. Behavioral arguments were quite common. There are so many patients, even in elite hospitals like mine. There was not even place to stand. | Is crowd a global problem in US hospitals as well? Or is it just in India? | Pratha Mandwal | New Question |
| : Planning for my appointment was my only responsibility those days. I didnt have any issues. My sister used to take me to appointments and plan accordingly. | No patient complained about planning appointments as a headache | Pratha Mandwal | New Hypothesis |
| I used my savings, friends and family were also kind to help me when my surgery happened in gurgaon, my sister gave me her house for around 15-20 days. She kept me with her. |  | Pratha Mandwal | General Insight |

**Interview Lead Source:**

**Transcript:**

**Interviewee: Alan**

**Interview Date: Thu, 06 Jan 2022 08:00:00 GMT**

**Notes:**

**Q: Could you provide information on how you used to process the incoming donations. Could you provide a breakdown of what was the processing fee, what were other fees?**

When we usually collect donations, something that has been really important for us is corporate matching programs, corporate matching programs, that when we when an employee of a corporation, or volunteers time or creates a donation to a validated nonprofit, that company actually matches dollar by dollar, the donation and that was actually say 80% of our revenues.

It was a donation of time. And for every hour that a volunteer worked with us, the company would pay us $20. Now, of course, not all the companies do that. But you should look into those that do because he was really really beneficial for us. Once we get the donation. Of course, we had a budget, which we would use to say, Okay, we want to spend the big thing that as you were alluding to, that people ask us, how do I know that the money is indeed helping the cause? And it's not just like paying their salary or any other administrative costs. And so, what I've seen a lot of nonprofits do is that on their website, there is this ratio, there's this graph that represents for every dollar that is donated to this organization, e.g., entrance since five cents, or whatever it is, goes to administrative processes, and the rest will go to actually helping people. And so, I don't know, off the top of my head, what was that percentage for us but it's usually between five and 20% of overhead costs for donation.

**Q: The company that was donating to you was donating volunteers, volunteers time along with the money that the company would donate. So, if I, as an employee of your company, decide to volunteer, the company starts to pay also, so basically, it's incentivizing me to volunteer my time?**

It has to come from the volunteer for the company does not go and does not select employees. The employees themselves, select the nonprofits and they volunteer, voluntarily and then on top of that, the company donates money.

**Q: You as a nonprofit were incentivizing or appealing to the engineers or employees in the organization via various marketing channels to reach them and incentivize them. So, they were one of your customer segments?**

Yes, so in our case, there was a very big overlap between the people that we wanted to help the people that were inside the company, you know, because maybe a few years ago, they were trying to learn computer science themselves. So, they really understood what it means to have the tools to learn and the programs and all that stuff. So, it was easy for us to get there. Attention and even though we did a good job, there's so much more we could have done in those big companies. I mean, there's just really a lot of people, a lot of people.

**Q: Could you explain more about the Meal Train that you have mentioned before?**

The Meal Train is similar. Because the meal train is something that let's say you get sick, and somebody needs to give you food and you're too sick to eat. So, it's a website where people that care about you basically go and either sign up to bring you a meal or pay so that you can get the food that you need.

I haven't actually used it. A friend of mine had cancer. A friend of his organized the meal train, which is a website and we all pitched in some amount of money so that they could get a meal every day and not have to worry. It's just like one thing less that they need to worry about.

**Q: What is your view on charging platform fees to target customers for creating their profiles?**

Initially, it feels a little bit of pudding but it's starting to make sense because you are indeed providing value and creating value for me because I no longer have to go and look at every single one of them. So, it's just not very common from my perspective to charge for that. For example, when I want to go to a hotel, I go to Trivago. In theory, that's what they do. They look for deals on many different hotels and many different places and use many different coupons, and they don't charge when you actually make a reservation.

Charging customers won’t be something that I would do as a first option. It feels strange because that's the person you're trying to help.

**Q: Do you think positively about charging some kind of money to even that donor who is donating some money as a value addition that we are providing to the donor thing?**

I think that makes a lot more sense. Because the donor by the mere fact that they are donating means that they have some sort of disposable income, right? It's not money that's going to prevent them from eating or from having a roof or something if they're donating, it's because they already have the money is not necessarily urgent for them. So, I would feel slightly better and in fact, many nonprofits do that. Like I was saying when you donate, some percentage of that is for the infrastructure of nonprofits, all the paperwork, all the websites or the salaries or like the administrative thing. I think it wouldn't be the first time in fact, I think that is just the norm, percentage of whatever you donate, and for the nonprofit.

**Q: Based on the concept of micro-donation, do you think we can build a model to sustain just with this much money? If you take 10% in extra fees from that, then you may get one dollar for every 10 dollars donated.**

No need to have a lot of volume to make that work. You will need to basically have thousands of transactions to make that sustainable. And when you again, I don't think that's going to be feasible. So you need to have some sort of bigger margin. strategy that's just kind of my first take on this because it would work taking a little bit of a lot of taking a small percentage of a small donation only makes sense if you're having a lot of donations. If you're not, then you would have to fight to increase your margin by taking a bigger either a bigger percentage or charging more money. Or the other alternative that I can think of is some weight making constant. Because if you instead of saying donate one time, and oh, you're a good person now. I need you to donate some amount every month. And I'm going to automatically at least protect you. Or maybe the margin is still close, but at least your minute you're reducing the risk of uncertainty because you know you have some certainty that month over month, you're gonna get some amount of revenue, and that feels better. And in fact, that's what a lot of the TV commercials like when you want to donate to St. Jude or when you want to donate to rent, I forget what the other ones are. But they ask for a monthly donation. They don't ask for a single one. And they do it for that same reason.

**Q: Could you explain more about the process of raising donations based on your experience? How hard is it to raise donations?**

Very hard. Very, very hard. We're very fortunate to have the corporate program that I was telling you about. Because if it weren't for that, I don't think we would have survived. So it was really tough. And we usually didn't really spend enough time looking for big donations from big corporations, like I would like you to donate $50,000 or something like that, or grants because actually getting grants is really, really tough. And you have to hire someone to actually do all the process and of course there's no guarantee that we had more. We had more success when we organized a gala dinner. So, we invited a lot of people in in the gala in the dinner, you have an opportunity to show what you're doing and to tell people hey, this is what I'm about to bring people that are beneficiaries of your nonprofit, and you have a lot of strategies to collect more money and that was useful to us. But in general, collecting donations is tough. My one recommendation would be that you need someone that has experience. First of all, you need to have a very sound business plan like a revenue model that works because in my mind, and other people disagree but you cannot rely on donations alone. You have to generate revenue in some way.

Unless of course you have the backing of somebody very famous or very big corporation. And most startups are not relying on donations, relying on telling people they hate please give me money. It's really really tough. So my strategy has always been needed to generate revenue by providing a service or a product or value or somehow generate something that people will give us money for while still growing our mission of being a nonprofit. But those two are not conflicted. Those two are not opposites of each other. So, you can feel something starch and you can feel help the people that you're trying to help. And so, I think that's been my approach. And there's certainly a lot of things we could say about how to go about donations. And I think we were just very fortunate by having Microsoft and Google and I think those were the two big ones because they have matching programs. So, the first thing that I would say is go to those companies that have matching programs. Try to find a group inside that is answered and does not discriminate. So, I'm pretty sure that there's a big amount of people that have come through this experience that see the need for what you're doing inside of the companies and the great thing about that is that you know they have money. And you know that the company has money because they have a matching program. The company has a matching program that has to mean that there's a culture of giving money to charity. So, and all those things are just like really good stuff for what you're doing.

**Q: Any platforms that provide people who are willing to donate?**

Benevity is the central platform that companies use to handle all the matching. So as long as you upload your organization to Benevity we're going to be available on all those companies.

**Q: What pitfalls do you see with building micro-donations?**

The biggest concern is that you need a lot of volume.

Costco, they make smaller, small margins but they have a lot of volume. But when you're starting, you don't have volume. Or there's no way for you to be competitive and to survive with low volume and small margin. So unless you can somehow tell me that you're going to get high volume, then I could see it happening. And I do think that it is something that could work. I've certainly seen that. So I don't know if this is a thing in the United States. Figure this out in the United States so when you go to the grocery store, and then your receipts, you can round up those cents, go to a charity. That's kind of the same thing. So, it's a micro-donation. You have to partner with somebody that again has the volume. You can do that then no problem.

**Q: What are the things that you see might work for us? What are the things that you believe are right, based on our definition?**

I do like the concept of micro-donation. I like it way more than bigger donations. So, I can see myself doing a micro-donation much more easily. So, if you just find a way to capture, I desire to donate. Just a micro-donation is beautiful, that's perfect. But again, you need a partner, you need a way to do that to increase your volume, but the mere fact that I can donate in a micro-volume, not believing in a microwave. I think that's appealing and that sparks my interest.

And the other thing that you mentioned is to donate to a particular person. So that was way more appealing than just donating to an organization. I don't know who's going to get the benefit. If I get somebody that needs care, I can immediately go to your platform and I know that my donation is going to help that person but it's also very appealing. So I think that's very positive.

**Q: Do you feel any resistance against the fact that:**

**If you donate 10 dollars, we might charge you two dollars as value addition fees and only eight rupees is going to help the needy person.**

I think that's fair. I think that's fine. And I think everybody does that thing that the standard and the monitors are saying the organization has to come from somewhere. And as long as you are as long as you lie about it, then that's fine. Even with all those crowdfunding websites, they take a cut of it. I take a cut of the transaction, credit cards they get side of the transaction, so it is not long as you're not bleeding people.

**Q: How do you see our organization growing right? What kind of inputs do you have on things that we can add to our business idea to make it more to make it more sustainable and to make it more attractive to the customers?**

1)Need somebody in the beginning that knows fundraising his own like his own world.   
Somebody that knows how to fundraise with extensive experience. This person will understand things, for example:

* Does that mean donations?
* Does that mean revenue?
* Does that mean grants?
* The partnership?
* The gala?

2)It would be nice to have somebody with a background like the medical aspect, you know, somebody that is the subject matter, experts dealing with patients that have gone through this is not critical because you're not literally doing anything health-related.

3)I also would recommend it doesn't have to be somebody new but just acquiring expertise in e.g., Are you going to make the money you know, it goes along with fundraising. Fundraising will be more like donation kind but if you want revenue like which revenue model are you going to do? Are you going to charge upon transaction? Are you going to charge month by month? Are you going to charge all that up?

**One of the important take-aways:**

One way we can get some volume is through partnerships with hospitals or someone who does have patients in bulk. Maybe with better marketing we can reach out to them but we will take your point into consideration and figure out ways in which we can either increase volume or increase margins.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |

**Transcript:**

**Interviewee: Theresa**

**Interview Date: Tue, 03 Aug 2021 12:29:20 GMT**

**Company: Caregiver**

**Notes:**

Interviewee : Dr Theresa Chang  
Dentist/ Caregiver : Old Age/ Patient in hospice.  
  
  
**Question:Since how long have you been looking after your patient?**  
14 months. After COVID, I have been looking after her full time.  
  
**Question: What’s your biggest challenge these days?**  
Caring for someone is expensive. It’s about 6000-12000 USD per month on average. On the  
higher end it’s around 10,000-15,000 USD.  
It’s a big industry, quite a few around here.  
I am in the midst of figuring out which option to pick for my mother. I don’t mind taking care of her, I had a  
very good relationship with her. It’s just pretty hard; this is a significant psychological challenge.  
My back hurts, my neck hurts. I feel she is not being appreciative. I try to see the humour sometimes, I  
know she is a great person.  
  
  
**Question: What are the problems with professional home providers?**  
Firstly, it's pretty expensive around $30 per her.  
Even if someone is coming to the house, then I will need to coordinate my shift. Moving her to an adult  
family home could be a way, my schedule is not so much tied to her. So that I can manage my schedule  
better.  
  
  
**Question: How do you plan your days?**  
I just changed my schedule to fit hers. I bring food to her, I hang out with her. She can’t feed  
herself. So, I have to be there when she is eating.  
I work around her schedule. She sleeps a lot, So, I try to manage.  
I would have liked to go hiking, I wouldn’t have a big chunk of time though. At best, I can have 4 hours  
free, So I plan in advance.  
  
**Question: So, then how do you plan then?**  
  
Lot of planning is required. No overnights, Sometimes, she could be having nightmares, she  
sometimes is sleep talking, i have to go in and check.  
I have to change my diet to softer food. Blended food most of the time.  
The heels of their body gets affected very early. There is enough pressure, it becomes red. You  
constantly need to monitor her. She can’t really speak.  
You need to talk to a nurse every couple of weeks.  
Tylenol to make her life a little easier. Cleaning her is not easy. Sponge bath her every day.  
Caregivers need to have a lot of empathy.  
  
  
**Question: What would you recommend to other caregivers?**  
Response: To be empathetic and patient. Mind set change needs to be done.  
Question: If there is a magical technology that could help you, what would it be?  
Response: If there is a support group that is going through the same thing, it will be super helpful. There  
are several for cancer patients, but I couldn’t find any for my case.  
Counselors who have faced the same thing, can help me so much more than the nurse and counselor  
line.  
I could benefit from talking to people, their journey, and what they are going through.  
  
**Question: How do you envision your support group?**  
Response: Group of people, who are going through the same thing, or have gone through it in the past,  
have made decisions to handle things.  
Chat! And Call! , on a topic - like ‘Deciding on moving to a home’  
Maybe just a bit of emotional encouragement. Or maybe just to vent sometimes.  
  
  
**Question: Would you pay for it?**  
Response: I am not sure if I would pay. Like, would I pay for facebook? Probably not.  
Maybe it could be donation based.  
Question: Which app helped you a lot in your caregiving journey?  
Response: App - NextDoor. Neighbourhood communication is pretty useful.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| Caring for someone is expensive. It’s about 6000-12000 USD per month on average. On the higher end it’s around 10,000-15,000 USD. It’s a big industry, quite a few around here. I am in the midst of figuring out which option to pick for my mother. I don’t mind taking care of her, I had a very good relationship with her. It’s just pretty hard; this is a significant psychological challenge. My back hurts, my neck hurts. I feel she is not being appreciative. I try to see the humour sometimes, I know she is a great person. |  | Pratha Mandwal | General Insight |

**Transcript:**

**Interviewee: Saima**

**Interview Date: Tue, 03 Aug 2021 12:25:47 GMT**

**Company: Cancer patient, caregiver**

**Notes:**

**Question: Tell me about yourself**  
  
My research dissertation topic is on the impact of social media on urban cancer survivors. I  
have interviewed more than 100 people, including caregivers. I have done content analysis of more than  
100 youtube videos.  
I have explored more than 50 accounts on instagram and facebook. I have done content analysis. I  
focussed primarily on facebook health groups, instagram stories and I have chosen blogs.  
So essentially I have talked to cancer patients, taking their permission to view their handle  
  
  
**Question: Based on your research, what’s your understanding on the role of social media?**  
See, after talking to all the cancer survivors. The key findings were  
Number one, people are not very comfortable talking to very professional counselors. Reason being,  
people do not feel emotionally attached to the counselor.. They feel that the counsellors do not  
understand what they are feeling.  
When you talk to someone who has gone through the same thing, then the question “Why me?” gets  
eliminated automatically. On a social media platform, you see 1000s of other people going through the  
same treatment. So the first thing that happens is “Why me?” gets eliminated. And once this is ‘why me?’  
get eliminated, then what happens is the next step which is hope. You cling onto hope.  
  
  
**Question: But what about the misinformation on social media?**  
  
Social media is a double-edged sword. It has always been, it will always be. But when I did the  
content analysis of Facebook health groups, I realized that these groups are very strictly monitored. These  
people are professionals, thorough professionals.  
If someone provides any misleading information, they are immediately removed. But then yes, this is a  
blanket statement. I am talking about a few select groups.  
Also, who said everyone uses social media for information? Some use social media for fundraising.  
Misinformation will be part of social media, yes it will always be till we reach on another level.  
Using blanket statements like that are not going to help.  
Also note that not everyone could afford a counsellor. Even AIIMS has pelitative counselor, but not  
professional counsellors.  
  
**Question: So, I recently interviewed a doctor who expressed his skeptism about the**  
**misinformation on social medi**a  
Response: I think that’s inaccurate because, actually the doctors recommend the patient to join social  
media groups. So that your apprehensions, your anxiety gets dissolved. To prepare oneself mentally, feel  
strong and connected.  
Cancer is all about will power  
  
  
**Question: Several caregiver’s reported that it’s hard to manage all the things that they have to do**  
**with the cancer patient. How can a caregiver manage his life with the cancer patient?**  
  
Have you been to any cancer restaurants recently ? I will give you a brief. I have been a  
caregiver from childhood. I lost both my parents to cancer. I myself got diagnosed a month back. So, if I  
tell you about the hospital settings, any renowned hospital is surrounded by PG and hotels which are  
making food based on the patient's needs. You can give them the list, and they will give you the food at  
the doorstep.  
After seeing the needs of the patients, the environment is evolving. You can find cheap PG, rents and  
flats for the patients.  
  
  
**Question: Then what do you think is the biggest problem for the caregiver?**  
I think the biggest problem is that the caregiver's life just stops. It totally depends on your  
monetary situation now.  
Have you heard about ‘Helping Souls?’ If you tell the hospital, I need an attendant for 6 hours, 8 hours  
etc to take care of the patient. Then you’ll get it easily. Hospital will assign you a completely capable  
person, to take care of the patient. But he will charge you hourly. He knows about injections, he is potty  
trained, he even knows when drip should be injected. But, then everything has heavy financial  
implications.  
  
**Question: What will be your input on how I can progress my investigation?**  
What’s your sample? What is your universe? Decide whom you’re targeting.  
Decide which caregivers? Which age group? Are the patients male or female? Are they female? Are you  
targeting urban or rural populations? Think if you have to do the field where you have to go? Every  
category has different needs, if the patient is a male, then the needs are completely different as opposed  
to if the patient is female. Also know that the needs of cancer survivors are completely different than the  
ones with cancer.  
Evaluate access to different means.  
Try to fix your title first. Make a flowchart. Decide on a framework. What are your basic research  
questions? What are your aims and objectives? Think, how practically your research is

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| Have you heard about ‘Helping Souls?’ If you tell the hospital, I need an attendant for 6 hours, 8 hours etc to take care of the patient. Then you’ll get it easily. Hospital will assign you a completely capable person, to take care of the patient. But he will charge you hourly. He knows about injections, he is potty trained, he even knows when drip should be injected. But, then everything has heavy financial implications. |  | Pratha Mandwal | General Insight |
| Number one, people are not very comfortable talking to very professional counselors. Reason being, people do not feel emotionally attached to the counselor.. They feel that the counsellors do not understand what they are feeling. When you talk to someone who has gone through the same thing, then the question “Why me?” gets eliminated automatically |  | Pratha Mandwal | General Insight |
| any renowned hospital is surrounded by PG and hotels which are making food based on the patient's needs. You can give them the list, and they will give you the food at the doorstep. |  | Pratha Mandwal | General Insight |
| Also, who said everyone uses social media for information? Some use social media for fundraising. |  | Pratha Mandwal | General Insight |

**Transcript:**

**Interviewee: Jyoti Ma'm**

**Interview Date: Tue, 03 Aug 2021 14:25:58 GMT**

**Notes:**

**Question: How did you get to know about your cancer?**  
  
Response: I got to know almost 1 year back. I never had any trouble health-wise. Due to the after-effects of cancer, I have lost almost 24 kgs in 1 year. Every 3 weeks, I have seating, it's a very painful process.  
  
**Question: Did the doctor refer you to any counselor?**  
  
Response: I understand the process, I understand the treatment. My body is responding positively to the treatment. I am an educated woman. I was a customs officer in the joint commission I don't need palliative care.  
  
**Question: Did you try Brahma kumari or another emotional support system?**  
  
Response: The concepts they teach are too high level. I don't understand such concepts.   
Also what qualifies these ladies to teach me life lessons? Have they been through cancer?   
  
**Question: How was your experience been talking to women in the Sangini group?**  
  
Response: The treatment process of most of these women is very simple, unlike mine. I have got a lung infection recently, and it was a very painful process. Most of these ladies have gone through a mastectomy and now take medicine once a year.  
  
**Question: Do you live alone?**  
  
Response: No, I live with my husband. But he is mostly busy, lost on his computer. I feel lonely,   
Sometimes, I feel hopeless. Sometimes, I am don't feel like living. It's been a year. I am still unable to accept.  
  
  
  
Additional Observation: The aunty was keen to know about my plans. How I am planning my travel and everything.

**Insights:**

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| **Quote** | **Comment** | **User** | **Finding Type** |
| : No, I live with my husband. But he is mostly busy, lost on his computer. I feel lonely,  Sometimes, I feel hopeless. Sometimes, I am don't feel like living. It's been a year. I am still unable to accep |  | Pratha Mandwal | General Insight |
| got to know almost 1 year back. I never had any trouble health-wise. Due to the after-effects of cancer, I have lost almost 24 kgs in 1 year. Every 3 weeks, I have seating, it's a very painful process. |  | Pratha Mandwal | General Insight |

**Transcript:**

**Interviewee: Dimple Bawa**

**Interview Date: Wed, 04 Aug 2021 18:38:08 GMT**

**Company: Social Worker**

**Notes:**

Dimple Bawa   
  
**Question: How did you deal with the diagnosis?**  
  
I had lost my mother to cancer so I was aware of the kind of Toll cancer takes on you. I was just not sure how it can affect me personally.  
I did not feel hopeless I was ok and I was not in the mood of denial.   
I thought about what I should do next I was said it was an unpleasant experience.  
  
**Question: Then what did you do?**  
  
It took some time to figure it out. But then I decided to empower myself with the right knowledge. I decided to take charge of my life. I decided to not be dependent on the doctor entire.   
What I realized is that doctors try to take advantage of our situation. I believe that a doctor should let us know all the options that we have. so I couldn't rely on one doctor.  
 I took multiple opinions. you know nothing changes in 10 to 15 days after the diagnosis. it's better to take time and completely understand what options you have.  
  
  
**Question. What's your opinion on supplementary medicine?**  
  
Don't fall for the commercial angle alone. if you believe in it go for it. alternative medicine is supposed to be supportive it's not for the primary use cases.  
  
Cancer treatment needs to take a holistic approach along with the allopathic medicines other therapies supportive treatments like Physiotherapy acupressure, muscular pain reliever oil needs to be encouraged.  
 we cannot consume junk and can still expect a healthy body.  
  
  
**Question: you mentioned cancer can be prevented can you please elaborate on that?**  
  
If you notice the causes of Cancer. genetic disorders contribute to 4:00 to 10%.  
  
Majority of the case is caused by bad habits such as alcohol abuse. due to abuse of alcohol liver gets compromised. Similarly, tobacco abuse in several forms like smoking chewing leads to 2 different forms of cancer such as lung cancer and oral cancer.  
Poor lifestyle such as physical mental and spiritual stress causes Cancer to relax. Food adulteration and toxic substances in water also contribute to cancer.  
What I am saying is that it could be avoided and this is what I refer to when I say you can prevent cancer.  
  
**Question: what are your thoughts on the stigma of cancer?**  
  
 I used to feel very angrily initially when people told me that cancer is the result of bad Karma. I thought to myself do I need to listen to this as well along with the diagnosis of Cancer.  
  
Nowadays I would tell cancer patients to meet me for coffee outside I would encourage them.  
Some of them haven't told anyone. So, then I make them realize that the way that they are dealt with ing cancer is suppressive. It's not like they have dealt with the car accident.  Rather than isolating themselves, they can reach out to people have a casual conversation with them. Talk to people about their Sufferings and get the support that they need.  
  
 Not just in rural society even educated people have stigmatized cancer.   
  
  
**Question: between 2013 and 2021 what has changed?**  
  
Corporate hospitals have come to support people. People who are no longer treating cancer as a death sentence are talking about it. between 2013 and 2021 the world has toppled down.  
  
 In 2003 when my mother was diagnosed with cancer I observed the treatment from a caregiver perspective. in 2013 when I was diagnosed I observed from survivor and patients perspectives.   
  
 I am pretty blunt if I feel that the doctor is not taking care of the patient not given them all options I just say it. I encourage others to do the same.  
  
**Question: how was your interaction with the social groups?**  
  
  
People have no idea what to do when they are diagnosed at first. when I first was diagnosed I talked to several survivors, caregivers, doctors and got all the information that I could.  
  
Initially, the doctor used to prevent me from checking the internet.  
They would say that it is filled with this information. However, I felt that they have a considerable amount of information online.  
When I shared it with them and ask them for their counsel based on the information that I have collected they were very happy about it.  
 They encouraged me, to share my experiences with others.  
  
**Question: what is your vision for the healthnest app?**  
  
We hope to engage and inform people we want to help and we want to stop the misinformation.  
  
we want to spread awareness about the prevention mechanism.  
  
We want to encourage positive lifestyle choices.  
  
we want to empower the patients who have just received the bad news of cancer diagnosis.  
  
  
**Question: what are your thoughts on caregiver issues?**  
  
The caregiver goes through a hell of a lot of trauma. I strongly believe they need to be counseling sessions by a psycho oncologist to help them and guide them through the process.  
One more thing the caregiver, immediate family members should not treat the patient differently.   
Of course, they should take care of the patient, but they should not mention that cancel is a result of bad Karma.  
  
**Question: thoughts on spirituality, meditation?**  
  
I think some engagement should be there to reduce stress. a cancer patient should also have something to look forward to apart from the treatment, something that brings them joy. but why does it need to be only Brahma Kumari? why can't it be simple things like going to a path cooking for themselves?  
 in hospitals, Brahmakumari is like a PR activity. hospitals make donations To The Spiritual organization, and spiritual organizations come to give life lessons to patients. in return the hospitals create videos and or themselves and the organization.  does Brahmakumari the pain of going through the treatment? No.  
  
I think rather than engaging in a single liver of spirituality hospitals need to promote engagement in general to Foster positivity among cancer patients.  
  
  
**Question: What are your fears as a survivor?**  
  
 I fear about my daughter. she is 20 now, after 5 years I hope to get her check-up done.   
I lost part of my body but I have learned to be happy in my own skin.  
 I am happy to share my experiences of my journey with people. I don't make any profit for myself. I do social work 100% philanthropy.  
Doctors have been advising patients to talk to me. It gives me immense pride.  
empowering everyone is my goal.  
I feel it's my responsibility to share my experiences with youth whoever it is is and whatever they are doing.

**Insights:**

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**Transcript:**