

**Vermont Comprehensive Cancer Control Program
Evaluation of the Kindred Connections
Cancer Survivor Peer Support Program
Final Report**



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I. EXECUTIVE SUMMARY

Kindred Connections (KC) facilitates peer-to-peer support of cancer survivors and their caregivers for all Vermont residents as part of the Vermont Cancer Survivor Network (VCSN). The Vermont Cancer Survivor Network coordinates with and is supported by the Vermont Comprehensive Cancer Control Program (VCCC). In July, 2016, the Vermont Department of Health/VCCC contracted with JSI Research & Training Institute, Inc. (JSI) to provide evaluation services to assess the impact of the KC program in implementing the cancer survivor quality of life objectives of the 2016-2020 Vermont Cancer Plan. Specifically, the evaluation was designed to explore how participation in Kindred Connections (KC) improves quality of life for participants and its members. The evaluation activities designed to answer this question include conducting focus groups with members (volunteers) and interviews with participants. Findings from the evaluation will be used to inform program performance, with the end goal of improving quality of life for cancer survivors.

One focus group with KC member volunteers and eight telephone interviews with KC participants were conducted between September, 2016 and April, 2017.

The following themes were identified from the focus group with KC members:

- 1. Involvement with Kindred Connections comes from personal experience and a desire to “give back”.** Focus group participants described that their motivation to be a KC member volunteer was from positive experiences of engaging with others with cancer; that “when you hear what everybody else is going through, and what you’re going through, and it’s great to share”. Others indicated wanting to improve circumstances for the next person diagnosed with cancer after not having had that support for themselves.
- 2. The community that is created through the shared experience of cancer can break down social boundaries.** Focus group participants described the cancer experience as something that changed them and that they can’t go back to “normal” even after treatment, underscoring the notion that one is never “done” with cancer. At the same time, this experience has created a sense of community for the volunteers that has been rewarding on a personal level. Serving as a KC member volunteer allows you to remain connected to cancer, acknowledging and addressing it as a significant part of one’s identity.
- 3. Connections can be made formally or informally.** Participants shared that they came to be part of KC through social media (Facebook posts), personal introductions by attending KC meetings, and social groups where KC members were participating in (e.g., singing groups). Members also shared about the KC “system” - a database accessed by the coordinator who matches the needs of participants with volunteers. These are the “formal” connections. But there are many that are also “informal”; connections made by being proactive in seizing opportunities.
- 4. Ongoing “support for the support” is necessary.** While focus group participants felt adequately prepared in providing support to participants based their own experience, some of the topics that were discussed such as the participant’s fear and anxiety about treatment or prognosis, and preparing for death were seen as more challenging. They expressed an interest in regular and organized trainings of member volunteers to share experiences and tips for handling difficult topics, as well as opportunities to debrief with one another. “Refresher” sessions were suggested at 6 months after the first training session. Training for volunteers who are providing support to participants regarding end of life care was of most interest. Another suggestion was

to follow up with volunteers after each connection through a survey to ask how the connection went and whether additional training or resources was required to support the participant.

The following themes were identified from the interviews with cancer survivors and caregivers:

- 1. The participant base of KC is diverse with complex needs and life situations.** Participants interviewed reflected the diverse participant base of Kindred Connections. While mostly women, they represented different cancer diagnoses, stages of cancer treatment, as well as socio-economic and educational backgrounds. Everyone described cancer survivorship as existing in a web of complex life situations – dealing with remission, a new round of treatment, job loss, housing instability, caring for young children, elderly parents, in-laws and adult children. The description of their life situations emphasized that while they were in need of support, there were others who were dependent on them.
- 2. Connections are fluid and flexible.** There are a variety of ways in which participants become connected to KC. Participants reported being referred by a social worker or care coordinator at the cancer center where they were receiving treatment. Others had found a KC flier and decided to call the number. One participant posted her status on her Facebook page and was connected through someone who saw the post. The type of connections that participants described ranged from “one time” interactions where the participant needed to talk to someone to help work through a decision and for reassurance, to interactions that span over a long period of time which invariably had turned into friendship where “we don’t talk about cancer”.
- 3. Matching on parallel experience is a key determinant of positive experience.** When cancer survivorship or taking care of a cancer survivor is seen as a journey, having someone come alongside, who is having a parallel experience, makes all the difference in having to take that journey. To carry the metaphor further, it is like someone who comes alongside and offers to carry your burden or the things that are weighing you down as you make the trek forward.
- 4. One-on-one attention is a unique need that Kindred Connections meet.** Given the often remote and rural nature of Vermont where transportation can present barriers, the option of receiving support by phone or email is a unique need that Kindred Connections meets. While many were part of cancer support groups in their communities, the one-on-one attention was seen as “easier than being with a whole group and hearing everybody’s spiel”, especially when “everybody’s dumping their problems, whatever’s happening, and it’s a lot, and there’s a lot of people, and a lot of need”. Moreover, the personal attention was prized because “it was all about me, and nothing is ever all about me.” Interviewees shared that having someone you can reach out to and was available for you (alone) made an incredible difference to their quality of life.
- 5. Volunteers are a vital source of local resources/information.** Volunteers are a critical connection point of local resources and knowledge. Interviewees commented on the resourcefulness of their volunteers in connecting them with other cancer survivors and events. This is especially helpful in remote parts of Vermont where availability of local services is even more important.
- 6. Misconceptions and Recommendations.** Participants reported that information about Kindred Connections was accessible through cancer treatment centers and through word of mouth. However there were some misconceptions about eligibility for support if one was receiving care

outside of Vermont. Another participant did not know that it was possible to meet up with their volunteer and was under the impression that the support was phone based. Others mentioned wishing they could have skyped or be able to video-chat with their volunteer. The expectations around the relationship were unclear in the beginning for one participant. One participant suggested a survey of participants at the beginning so that the volunteer has an understanding of the immediate situation and needs of the participant in the initial call.

The following recommendations are offered for consideration:

1. Enhance structure in the connection process for both volunteers and participants.

Kindred Connections is a volunteer-run organization with limited capacity and resources. It is important that KC maintains the “grassroots” nature of the organization while adding some structured processes to better support volunteers and withstand turnover of volunteers/staff and to maintain sustainability. This may start with a mapping exercise conducted with KC leadership to understand “who does what” throughout the connection process for volunteers and participants. The mapping would document existing processes and identify additional steps to improve the process. For example, for volunteers, this may start at recruitment or “intake” stage to incorporate a standard assessment for experience and comfort level in offering peer support, but include questions about other skills and interests. Similarly, for members, a standard set of questions that assess social needs and family/living situation would be helpful to establish the type of support or resources that participants are in need of.

Other suggestions from participants include providing written information about the respective roles of both volunteers and participants. This step would be helpful to establish a realistic expectation of the connection. Creating an avenue for members and participants to “debrief” their connection encounter would enhance support of the connection and provide feedback for continuous quality improvement purposes. This might be in the form of an online private forum for members to share experiences and ask questions/advice.

2. Maintain and diversify the volunteer base.

To ensure sustainability of a volunteer-run organization, it is important to match volunteer skills with appropriate assignments. There may be cancer survivors and/or caregivers who would like to be KC members but are more comfortable with roles and responsibilities other than offering peer support to cancer survivors. KC can use the volunteer recruitment/intake/orientation process to leverage other skills that members can offer. This may be in discrete tasks such as writing a monthly blog, or organizing celebrating events, or creating and updating a membership database.

Engagement of KC volunteers can be through offering “refresher” training opportunities to develop their skills in peer-support. Members mentioned challenging topics such as end of life, dealing with fear and anxiety. This may be done through an annual survey of members to identify topics of interest, or collecting training needs when debriefing with members. Distributing training opportunities offered by other community based organizations may help to alleviate the need for additional resources (trainers, space, etc) that KC may not have access to.

3. Promote Kindred Connections

It is noted that clear and concise messaging about what Kindred Connections “is” and “does” needs to be available on the KC website. While much of the information is relayed by word of mouth, misinformation can be promulgated if there is no standard description of the organization and its purposes. Consider creating a one-pager about KC that is downloadable from the website so that members and volunteers can print and distribute as needed.

There are many roads that can lead a volunteer or a participant to KC. While many participants mentioned being referred by a social worker or navigator at their cancer center, readiness to engage in peer support may come later. Increasing awareness of local primary care providers about KC may offer an opportunity to connect cancer survivors with peer support at a point when they may be more ready or in need of the “one-on-one” attention that is unique to KC.

II. INTRODUCTION AND BACKGROUND

More than 15.5 million Americans with a history of cancer were alive on January 1, 2016, and it is estimated that by January 1, 2026, the population of cancer survivors will increase to 20.3 million.¹ Peer support can be valuable across the cancer continuum; from diagnosis to treatment and post-treatment. Studies examining peer support among cancer survivors have demonstrated high levels of satisfaction², citing its informational, emotional and instrumental benefits.³

Kindred Connections (KC) facilitates peer-to-peer support of cancer survivors and their caregivers for all Vermont residents as part of the Vermont Cancer Survivor Network (VCSN). The Vermont Cancer Survivor Network coordinates with and is supported by the Vermont Comprehensive Cancer Control Program (VCCC). As of July 2015, there are 113 active members (mostly cancer survivors, some caregivers) representing 7 counties in the state. Part of VCCC's Evaluation Plan (January, 2016) aims to assess the impact of the 2016-2020 Vermont Cancer Plan and to measure and improve the effectiveness of VCCC programs, inform future program and coalition development, and to demonstrate accountability to funders.

In July, 2016, the Vermont Department of Health/VCCC contracted with JSI Research & Training Institute, Inc. (JSI) to provide evaluation services to assess the impact of the KC program in implementing the cancer survivor quality of life objectives of the 2016-2020 Vermont Cancer Plan. Specifically, the evaluation was designed to explore how participation in Kindred Connections (KC) improves quality of life for participants and its members. The evaluation activities designed to answer this question include conducting focus groups with members (volunteers) and interviews with participants. Findings from the evaluation will be used to inform program performance, with the end goal of improving quality of life for cancer survivors. The contract period, originally from July, 2016 to March, 2017, was extended to June 30, 2017.

III. METHODOLOGY

JSI takes a collaborative approach to evaluation. JSI worked closely with Vermont Department of Health (VDH) staff to review and refine the evaluation plan to assess the impact of the KC program, and develop a timeline to implement the scope of work. Key components of the evaluation are described below.

A. Guide Development

JSI reviewed and made modifications to the Focus Group (FG) Guide that had been originally developed by the VDH Public Health Analyst II (submitted to VT Agency of Human Services (AHS) IRB. The FG Guide (see Appendix A) included a cover page that described the purpose of the focus group, its procedures, risks and benefits and processes for ensuring confidentiality. The Key Informant Interview (KII) Guide was developed by JSI and followed the same introductory format to obtain verbal consent with interviewees (see Appendix B). The focus group was designed to be an hour and a half in length, while the interview was designed to take 30-40 minutes.

¹ American Cancer Society, Cancer Treatment and Survivorship Facts and Figures, 2016-2017. (<https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-treatment-and-survivorship-facts-and-figures/cancer-treatment-and-survivorship-facts-and-figures-2016-2017.pdf>) Accessed 6.6.17.

² Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling*, 2008; 70, 315-337.

³ Campbell, H.S., Phanuel, M.R. and Deane, K. Cancer Peer Support Programs – do they work? *Patient Education and Counseling*, 2004; 55, 3-15.

B. Recruitment

Focus group participants were recruited via a Kindred Connections celebration scheduled on September 17, 2016 in Barre, VT. Volunteers taking part in the celebration were invited to stay after the celebration to participate in a focus group discussion about their experience as KC members. Participants who had agreed to participate were reminded during event registration. Of 33 potential participants, eight stayed for the focus group. Light refreshments were provided for the participants.

Recruitment of KC participants (cancer survivors and caregivers) was facilitated by Kindred Connections. A recruitment flyer (see Appendix B) describing the purpose of the interviews was created and distributed via email through KC's member network. With a low yield of interested participants, JSI proposed alternate recruitment strategies including involvement of the newly hired KC Coordinator to facilitate targeted recruitment. Of 12 potential KC participants contacted, eight agreed to be interviewed. Interviews took place at a time convenient for the participant. This included before hours, in the evenings and on the weekend.

C. Consent and Participant Pre-Survey

The focus group facilitator explained the consent process and informed the participants that the focus group would be audio-recorded for note-taking and analytic purposes. Focus group participants were asked to complete a survey to provide demographic information before the focus group discussion commenced. Similarly, verbal consent and permission to audio-record the interviews for transcription purposes were obtained from all interviewees. Interviewees also completed a brief pre-survey to ascertain whether they were a caregiver or survivor, their age group and county of residence.

D. Analysis

The focus group discussion and seven of the eight interviews were transcribed. (One of the interviews was unintelligible as the interviewee was in her car at the time of the interview. Analysis for this interview was through interview notes). Memos were written by the interviewer (JC) to document themes emerging after each interview. Next, transcriptions of each interview were reviewed for common themes. Emerging themes noted in the memos and themes from analysis of transcriptions were compared to finalize key themes. Quotes to support the themes were recorded. Viewpoints that did not conform to the themes were noted.

IV. FINDINGS

A. Focus Group with Kindred Connections Members

Participant Demographics

There were eight focus group participants; seven female, one male; the majority of who were between 50-69 years old and resided in Washington County. Others were from Chittenden County and Orange County. Two of the participants had been members of KC between one to two years; the others had been involved with KC for three years or more, with three members having been part of KC for more than five years. All but one of the participants is a cancer survivor.

Key Themes

- 1. Involvement with Kindred Connections comes from personal experience and a desire to "give back".*** Focus group participants described that their motivation to be a KC member volunteer was from positive experiences of engaging with others with cancer; that "when you hear what

everybody else is going through, and what you're going through, and it's great to share". Others indicated wanting to improve circumstances for the next person diagnosed with cancer after not having had that support for themselves.

"For me, it was the fact that I hadn't had very much support when I was diagnosed. And so, I felt like other people might be in that same position. And so, that's why I joined."

"I missed being able to talk to someone who had been through a similar experience. So that, after my treatment, I just kind of let it be known that if anyone was going through any kind of cancer treatment and had questions, to contact me."

Participants shared that the extra benefit of making connections with other cancer survivors was the bi-directional nature of "receiving even as you give".

"And I would just add to that, that there's not just not one way, because when you're helping other people, and really just listening to them, it's also a benefit, at least for me, it's a benefit to be able to do that for people".

"I think of it as a lifeline, you know, somebody threw one to us when we were in need, so now, we can throw one back to somebody, and help them out. So it's believing that we are helping making someone's life a little bit easier, or a little less scary, because we can share our experiences with them."

- 2. The community that is created through the shared experience of cancer can break down social boundaries.** Focus group participants described the cancer experience as something that changed them and that they can't go back to "normal" even after treatment, underscoring the notion that one is never "done" with cancer. At the same time, this experience has created a sense of community for the volunteers that has been rewarding on a personal level. Serving as a KC member volunteer allows you to remain connected to cancer, acknowledging and addressing it as a significant part of one's identity.

"It's still a very big part of me. It's changed me. And so that is a way that I can still stay connected to that part of me, but yet, I'm still moving in other circles too".

"You know, that's like it is who you are, and it's the very fabric of who you are. So, helping other people helps you acknowledge that it's still part of who you are, but it isn't your being per se, like you are another person with this thing, and it's acknowledging that other thing".

The experience of cancer has the ability to break down boundaries between roles that we have in society. Cancer essentially "levels" the playing field. One participant shared her experience when she learned that her employee's mother was diagnosed with blood cancer.

"I would check in with him pretty regularly just to see how things were going. And I got him to come to a support group meeting up in Burlington. But it was interesting, because I told him very early on, I said, you know, I'm not your boss, I am another person who deals with cancer... It was interesting to be able to take one hat off, and put another hat on, and be able to help somebody who was in their darkest times."

- 3. Connections can be made formally or informally.** Participants shared that they came to be part of KC through social media (Facebook posts), personal introductions by attending KC meetings, and social groups where KC members were participating in (e.g., singing groups). Members also shared about the KC "system" - a database accessed by the coordinator who matches the

needs of participants with volunteers. These are the “formal” connections. But there are many that are also “informal”; connections made by being proactive in seizing opportunities.

“People don't have to sit, and wait for connection, people go through training, and learn – listening skills, and things to ask about, and things not to do, you know, the whole training piece that goes with it. And it's like well, you don't have to wait for someone to call you, if you know somebody with cancer, give them a call, and say you know, who we are, and, you know, what's your – who you're with, and – talk to them.”

Volunteers use different modes of communication with same person - phone, email, in-person, social media. All modes can be used for the same person. In Vermont where geographical distance can separate people, phone and email are most common.

4. ***Ongoing “support for the support” is necessary.*** While focus group participants felt adequately prepared in providing support to participants based their own experience, some of the topics that were discussed such as the participant’s fear and anxiety about treatment or prognosis, and preparing for death were seen as more challenging. They expressed an interest in regular and organized trainings of member volunteers to share experiences and tips for handling difficult topics, as well as opportunities to debrief with one another. “Refresher” sessions were suggested at 6 months after the first training session. Training for volunteers who are providing support to participants regarding end of life care was of most interest. Another suggestion was to follow up with volunteers after each connection through a survey to ask how the connection went and whether additional training or resources was required to support the participant.

Overall, the experience of being a KC member volunteer was positive. Volunteers appreciated the flexibility in the commitment, knowing that “there are times when I have to say I can’t”. As one volunteer recalled, she did not take on a new connection because she did not have the emotional energy.

B. Interviews with Kindred Connections Participants

Participant Demographics

There were eight KC participants interviewed; one male and seven female. Six interviewees identified as cancer survivors and two were caregivers. Participants were from Chittenden, Washington, Bennington and Grand Isle Counties. While interviewees ranged from 31-70 years, the majority were between 51-60 years. Among the cancer survivors, breast cancer was the most common cancer diagnosis.

Key Themes

1. ***The participant base of KC is diverse with complex needs and life situations.*** Participants interviewed reflected the diverse participant base of Kindred Connections. While mostly women, they represented different cancer diagnoses, stages of cancer treatment, as well as socio-economic and educational backgrounds. Everyone described cancer survivorship as existing in a web of complex life situations – dealing with remission, a new round of treatment, job loss, housing instability, caring for young children, elderly parents, in-laws and adult children. The description of their life situations emphasized that while they were in need of support, there were others who were dependent on them.
2. ***Connections are fluid and flexible.*** There are a variety of ways in which participants become connected to KC. Participants reported being referred by a social worker or care coordinator at

the cancer center where they were receiving treatment. Others had found a KC flier and decided to call the number. One participant posted her status on her Facebook page and was connected through someone who saw the post. The type of connections that participants described ranged from “one time” interactions where the participant needed to talk to someone to help work through a decision and for reassurance, to interactions that span over a long period of time which invariably had turned into friendship where “we don’t talk about cancer”. The modalities in which interactions occur have flexibility and are dependent on the need of the participant. Some keep in touch by social media, email or phone and never met their volunteer in person; others have in-person interactions and attend cancer support groups and retreats together.

- 3. *Matching on parallel experience is a key determinant of positive experience.*** When cancer survivorship or taking care of a cancer survivor is seen as a journey, having someone come alongside, who is having a parallel experience, makes all the difference in having to take that journey. To carry the metaphor further, it is like someone who comes alongside and offers to carry your burden or the things that are weighing you down as you make the trek forward.

“It’s pretty phenomenal cause when you join the world of cancer survivorship, that’s what your friendship base kind of becomes...you know, my friends are well meaning, but have never been through this journey don’t understand what these ladies understand, you know, what [volunteer] understands.”

It’s the commonality of the diagnosis. We had a common experience, a shared lived experience, someone who can say, “I know where you’re coming from.”

“I don’t know how else to describe it other than family’s great, but when you’re going through that kind of journey, this is an important...Having somebody to just understands and can just sit and listen and hear your concerns, and know, actually know, having experienced it. So that’s what’s been important to me, and that’s what’s been extremely helpful”.

The matching of a KC volunteer to a participant’s cancer diagnosis was acknowledged to be difficult but something that made the difference in support received. It was not only about the diagnosis but knowing that the volunteer was “somebody who has gone through this whole thing” and “it was good for me”.

“Knowing someone out there who not only had the same experience and survived but who had made the decision to reach out and become a resource in her own way, knowing that that person had made that kind of commitment, I think made it both easier and more rewarding to communicate with her because she put herself out there for that express purpose.”

- 4. *One-on-one attention is a unique need that Kindred Connections meet.*** Given the often remote and rural nature of Vermont where transportation can present barriers, the option of receiving support by phone or email is a unique need that Kindred Connections meets. While many were part of cancer support groups in their communities, the one-on-one attention was seen as “easier than being with a whole group and hearing everybody’s spiel”, especially when “everybody’s dumping their problems, whatever’s happening, and it’s a lot, and there’s a lot of people, and a lot of need”. Moreover, the personal attention was prized because “it was all about me, and nothing is ever all about me.” Interviewees shared that having someone you can

reach out to and was available for you (alone) made an incredible difference to their quality of life.

“But I think for me what the volunteer offered was not only someone to answer questions, but someone whom I could reach out to that was just there for me”

“I think knowing that person was there and as really available to talk or for support or a shoulder to cry on or we needed someone to pick up groceries or whatever...just know that she was there.”

“Somebody that gives you your one-on-one is their one-on-one attention. That’s awesome because you know that person’s listening, that person’s engaged in what you’re saying. And to me, that is essential when you’re going through some journey like this.”

Kindred Connections volunteers have a unique role in support of cancer survivors and their caregivers. Primarily it is because they are “not family” and were seen as “objective” without the “emotional baggage”.

“I think for me, it’s somebody that doesn’t have the emotional involvement so they can look at something objectively, and tell me if I am that, pardon the expression, batshit crazy. Or if you know, I mean, they could be honest with me and not try to worry about my feelings or whatever.”

“She has been incredibly thoughtful, and considerate, and has gone out of her way to make sure that if I had any questions, or had any concerns that there was somebody that would listen. Not that she necessarily had gone through that, but that she could be an ear that is not a family member, but somebody that has had a similar journey.”

However, at times, offering emotional support may not be enough. One interviewee shared that her cancer diagnosis and treatment had caused significant financial trouble and family stress. These cases call for referral to appropriate community services resources that may be beyond the knowledge base of the KC volunteer.

- 5. *Volunteers are a vital source of local resources/information.*** Volunteers are a critical connection point of local resources and knowledge. Interviewees commented on the resourcefulness of their volunteers in connecting them with other cancer survivors and events. This is especially helpful in remote parts of Vermont where availability of local services is even more important.

“She also would send out information about different events that are going on around for cancer survivors. Different workshops, or different retreats. And she’s always telling everybody about “Okay, do this. This is free, this costs this much” There might be scholarships...she’s always sending out that information and digging for more all the time”

- 6. *Misconceptions and Recommendations.*** Participants reported that information about Kindred Connections was accessible through cancer treatment centers and through word of mouth. However there were some misconceptions about eligibility for support if one was receiving care outside of Vermont. Another participant did not know that it was a possible to meet up with

their volunteer and was under the impression that the support was phone based. Others mentioned wishing they could have skyped or be able to video-chat with their volunteer.

The expectations around the relationship were unclear in the beginning for one participant. One participant suggested a survey of participants at the beginning so that the volunteer has an understanding of the immediate situation and needs of the participant in the initial call.

“I think people’s needs exist on a continuum. It might be helpful to almost survey the individual participating about where they are, what they would like to talk about, or using a scale to what extent are you worried about the future ...and let them know we’re going to share this with your volunteer...so that volunteer has some sensitivity to the [participant] when she speaks with you. Otherwise you have this intimate bridge of shared experience in the disease process that people are going through, and yet the person is a total stranger... If [volunteer] had known what I had going on at home, she could ask me right off the bat, so what’s going on with your mother-in-law”.

Many participants interviewed were interested in becoming a Kindred Connections volunteer themselves. Some had or were planning to attend a training that was being scheduled. However, one interviewee cautioned that not all participants were ready to engage as a volunteer and asked for greater sensitivity when making the call for volunteers. Printed information about Kindred Connections in the form of a postcard was suggested as something helpful to be able to share with others that participants might meet.

V. DISCUSSION

Both volunteers and participants expressed that being part of Kindred Connections improved their quality of life. For volunteers, it was both the benefit of connecting with their identity as a cancer survivor in a positive way and being able to “give back” to the larger cancer survivor community by offering to share their personal experience with someone else on the same “journey”. For participants, the support through KC represented a space dedicated to them alone, especially as cancer survivorship exists in a complex web of life situations where “nothing is ever all about me”. The unique one-on-one attention that they received, the shared experience with their volunteer and the friendship and bond that emerged as part of the connection were all valuable aspects of the KC experience. At the same time, a connection with KC members opened up opportunities to learn about local resources and created a connection point to the larger network of cancer survivors in their local community.

The role of caregivers can be overlooked in cancer survivorship. The resources and support for caregivers that KC provides is also worth noting. While caregivers may be a small percentage of KC participants, they benefitted indirectly from the support their spouse received or directly from other caregivers. The direct support between caregivers represents an opportunity in enhancing the quality of life among cancer survivors and their families.

The flexibility and organic nature of connections was valued by both KC members and participants. Members appreciated that their commitment level could be adapted depending on other demands on their time and energy. KC participants appreciated the flexibility of the connections which was different to committing to a more formal cancer support group. There was an understanding that the level of communication with the volunteer was “on their own terms” which is something needed when going through cancer treatment.

Limitations

There are some limitations to the findings of this study, stemming from the small sample size and sampling strategy. Recruitment of participants for both focus groups and interviews was facilitated by KC which had limited capacity at the time of study implementation. This method of “convenience sampling” can undermine the representativeness of responses to the larger KC membership and participant base. Convenience sampling can run the risk of selection bias meaning those recruited may be more amenable to participating due to a positive experience with the program, thus missing the perspective of those who did not have a positive experience. While it is known that women make up the majority of members and participants, the under-representation of the male perspective is noted. For example, while women value emotional support, other types of support from KC members may be more meaningful for men who are cancer survivors.

VI. RECOMMENDATIONS

Through a process of discussion with VDH staff and other stakeholders, the following recommendations are offered for consideration.

1. Enhance structure in the connection process for both volunteers and participants.

Kindred Connections is a volunteer-run organization with limited capacity and resources. It is important that KC maintains the “grassroots” nature of the organization while adding some structured processes to better support volunteers and withstand turnover of volunteers/staff and to maintain sustainability. This may start with a mapping exercise conducted with KC leadership to understand “who does what” throughout the connection process for volunteers and participants. The mapping would document existing processes and identify additional steps to improve the process. For example, for volunteers, this may start at recruitment or “intake” stage to incorporate a standard assessment for experience and comfort level in offering peer support, but include questions about other skills and interests. Similarly, for members, a standard set of questions that assess social needs and family/living situation would be helpful to establish the type of support or resources that participants are in need of.

Other suggestions from participants include providing written information about the respective roles of both volunteers and participants. This step would be helpful to establish a realistic expectation of the connection. Creating an avenue for members and participants to “debrief” their connection encounter would enhance support of the connection and provide feedback for continuous quality improvement purposes. This might be in the form of an online private forum for members to share experiences and ask questions/advice.

2. Maintain and diversify the volunteer base.

To ensure sustainability of a volunteer-run organization, it is important to match volunteer skills with appropriate assignments. There may be cancer survivors and/or caregivers who would like to be KC members but are more comfortable with roles and responsibilities other than offering peer support to cancer survivors. KC can use the volunteer recruitment/intake/orientation process to leverage other skills that members can offer. This may be in discrete tasks such as writing a monthly blog, or organizing celebrating events, or creating and updating a membership database.

Engagement of KC volunteers can be through offering “refresher” training opportunities to develop their skills in peer-support. Members mentioned challenging topics such as end of life, dealing with

fear and anxiety. This may be done through an annual survey of members to identify topics of interest, or collecting training needs when debriefing with members. Distributing training opportunities offered by other community based organizations may help to alleviate the need for additional resources (trainers, space, etc) that KC may not have access to.

3. Promote Kindred Connections

It is noted that clear and concise messaging about what Kindred Connections “is” and “does” needs to be available on the KC website. While much of the information is relayed by word of mouth, misinformation can be promulgated if there is no standard description of the organization and its purposes. Consider creating a one-pager about KC that is downloadable from the website so that members and volunteers can print and distribute as needed.

There are many roads that can lead a volunteer or a participant to KC. While many participants mentioned being referred by a social worker or navigator at their cancer center, readiness to engage in peer support may come later. Increasing awareness of local primary care providers about KC may offer an opportunity to connect cancer survivors with peer support at a point when they may be more ready or in need of the “one-on-one” attention that is unique to KC.

VII. APPENDICES

Appendix A: Focus Group Guide

Appendix B: Interview Guide and Recruitment Flyer

*Evaluation of the Kindred Connections cancer survivor peer support program***Kindred Connections Members Focus Group Guide****Intro** (read to participants and/or provide written copy):

Good afternoon! Thank you for meeting with us today to talk about your experiences with the Kindred Connections. My name is xxx and I will facilitate this afternoon's discussion. Before we begin, I have some information to share with you about the purpose of the focus group and how we will proceed. You can refer to it in your hand-out. I will be asking each of you to consent to participating in the focus group by signing the bottom of the hand-out.

Purpose:

The purpose of this focus group is to learn more about how you, as a Kindred Connections volunteer/member, support other cancer survivors/caregivers. We are interested in understanding what type(s) of support you provide, and how you provide that support. We also want to know what benefits you receive from being a volunteer, any challenges you face in providing support, and what Kindred Connections could do to help you address those challenges. The goal of this focus group, and other evaluation activities, is to improve Kindred Connections and, by extension, the lives of cancer survivors in Vermont. The results may also be used in a peer-reviewed journal article describing the support available to cancer survivors in Vermont.

Procedures:

Participation in the focus group is entirely voluntary, and you are free to leave at any time. The focus group is being conducted by a trained focus group moderator from JSI, a firm which has been contracted by the Vermont Department of Health Comprehensive Cancer Control Program and Vermonters Taking Action Against Cancer (VTAAC), with input from the Vermont Cancer Survivor Network, to assist in the evaluation of Kindred Connections. The focus group will include 8-12 Kindred Connections members from around Vermont and will last one hour. The focus group will be audio recorded so that all comments can be transcribed. No leaders from the Vermont Cancer Survivor Network, Kindred Connection, or representatives from the Department of Health will be present during this discussion, and your comments will not be linked to your names. However, if any of you do not feel comfortable having the tape recorder on, please let me know and we will not use it.

Risks and Benefits:

The risks for your involvement in this focus group are minimal. All participants are asked to respect the privacy of other participants and to not disclose anything said in the context of this discussion. However, it is important for you to understand that other participants may not keep all information private. You will not receive any direct benefits from participating in this focus group. However, the information gleaned from this focus group may improve the Kindred Connections program.

Confidentiality:

The audio recordings of the focus group will be transcribed by the contracted firm JSI and will not be shared with the Department of Health, VTAAC, VCSN or Kindred Connections. The transcripts will be shared with the Department of Health after all individual identifying information (e.g. name, town of residence, etc.) have been removed. No individual participant will be identified or linked to the results. Results will be shared with Kindred Connections, VCSN, VTAAC and the Department of Health when all portions of the evaluation have concluded (likely Spring 2017).

All participants are asked to respect the privacy of other participants and to not disclose anything said in the context of this discussion.

Questions:

If you have any questions or concerns, please contact:

Leanne Shulman, Public Health Analyst, Vermont Department of Health at (802) 951-1211 or at leanne.shulman@vermont.gov

Before we begin, do you have any questions?

OK, let's begin!

Evaluation of the Kindred Connections cancer survivor peer support program

Opening:

To start, I'd like to understand more about how you became involved with Kindred Connections.

[Spend 10 minutes at most in this part of the FG as warming up and learning about general experience as KC volunteers. No need to ask each person to answer each of the questions; get a show of hands and ask for anything else not mentioned]

- How did you come to learn about Kindred Connections?
- How long have you been involved with Kindred Connections?
- Why did you decide to become involved as a volunteer with Kindred Connections?
 - What were you hoping to accomplish as a volunteer? How's it going so far?

I'd like to learn how volunteers are providing support to cancer survivors and the types of support. This first set of questions is about the most recent connection you made:

[Move through Questions 1-3 quickly; list responses, ask for anything else not mentioned.]

1. Thinking of the most recent occasion you provided a cancer survivor or caregiver with support, how did you make the connection?
2. How did you provide support (e.g. phone call, in person, email)?
 - a. Was this a once-off activity or on-going?
3. What topics did you discuss with the participant (e.g. your experience with the medical system, fears of death, etc.)?
4. Did you feel adequately prepared for the issues that came up?
5. What would have been helpful for you to be able to address the issues that came up?
 - a. Is there anything you would have done/said differently?
6. Are there resources or information you would like to have available to help you provide support to the cancer survivors and/or caregivers you work with?
7. Along those lines, do you have any recommendations for the training that you received as a Kindred Connections volunteer?

This second set of questions addresses all the connections you have made through Kindred Connections

1. Tell me about an occasion when you provided support where you felt you made a difference for the survivor/caregiver. [describe a positive experience]
2. Have you encountered any situations when providing support that you felt you were unable to handle? What did you do? [describe a negative experience]
3. How could Kindred Connections, as a program, help you better manage or prepare for difficult situations when you are providing support?
 - a. Did the initial training help you prepare for difficult situations?

4. What kind of continued support do you need to help you with your support of KC participants? [probe: resources, training, opportunity to debrief with a counselor?]

[Time check: if time allows, proceed with the following questions. If not, ask the closing question.]

5. Have you ever considered discontinuing your role as a volunteer for Kindred Connections? If so, could you share why?
6. Why do you continue to be involved with Kindred Connections? What about the program or your role encourages you to continue doing this work?
7. How do you think the program is valuable for survivors? How does the program enhance the survivor's quality of life?

Conclusion:

Is there anything about Kindred Connections that I have not asked about that you would like to share?

*Evaluation of the Kindred Connections cancer survivor peer support program***Focus Group Participant Survey**

Thank you for agreeing to participate in the focus group this afternoon. Please take a couple of minutes to respond to the following questions. The information you provide will be summarized to describe the participants attending the focus group today.

1. Please indicate your gender: Male _____ Female _____ Gender non-conforming _____
2. Please indicate your age group
Less than 30 years _____
30-39 years _____
40-49 years _____
50-59 years _____
60-69 years _____
70 years and above _____
3. What is your county of residence? _____
4. How long (months or years) have you been a member of Kindred Connections?
_____ months, or _____ years
5. On average, how many hours per week do you spend providing support to cancer survivors? _____
6. Are you a cancer survivor? Yes _____ No _____ Prefer not answer _____

Kindred Connections Participant Interview Guide**Introduction**

Good morning/afternoon! Thank you for your interest in talking about your experiences with the Kindred Connections. My name is Jocelyn Chu and I will be conducting the interview. Before we begin, I have some information to share with you about the purpose of the interview and how we will proceed. You can refer to it in the document I had sent you. I will be asking you to provide verbal consent to participating in the interview.

Purpose:

The purpose of this interview is to learn about your interactions with a Kindred Connections volunteer. We are interested in hearing how often you interacted with a Kindred Connections volunteer, what type(s) of interactions you had, and any benefits or harms you experienced as a result of those interactions. We will also ask what you think could be done to improve Kindred Connections.

The goal of this interview, and those with others who have interacted with Kindred Connections volunteers, is to improve Kindred Connections and, by extension, the lives of cancer survivors in Vermont. The results may also be used in a peer-reviewed journal article describing the services available to cancer survivors in Vermont.

Procedures:

Participation in this evaluation project is entirely voluntary, and you are free to end the interview at any time or skip any question you do not wish to answer. I am a trained interviewer from JSI, a firm which has been contracted by the Vermont Department of Health Comprehensive Cancer Control Program and Vermonters Taking Action Against Cancer (VTAAC), with input from the Vermont Cancer Survivor Network, to assist in the evaluation of Kindred Connections. We are conducting interviews with cancer survivors and caregivers around Vermont who have interacted with Kindred Connections volunteers. This interview will last approximately thirty minutes. The interview will be audio recorded to allow for our conversation to be transcribed. There are not any representatives of the Vermont Cancer Survivor Network or Kindred Connections leadership, or representatives from the Health Department on this call or who will hear this recording, and your comments will not be linked to your name.

Compensation:

If you agree to participate, following this interview you will be sent a \$30 grocery gift card to reimburse your valuable time.

Risks and Benefits:

The risks for your involvement in this evaluation project are minimal. You will not receive any direct benefits from participating in this evaluation project. However, the results may improve the Kindred Connections program.

Confidentiality:

The audio recordings of all the interviews will be transcribed by the contracted firm JSI and will not be shared with the Department of Health, VTAAC, VCSN or Kindred Connections. The transcripts will be shared with Department of Health after all individual identifying information (e.g. name, town of residence, etc.) have been removed. No individual participant will be identified or linked to the results. Results will be shared with Kindred Connections, VCSN, VTAAC and the Department of Health via a report when all portions of the evaluation have concluded (likely Spring 2017).

Questions:

If you have any questions or concerns please contact: Sharon Mallory, Coordinator, Comprehensive Cancer Control Program, Vermont Department of Health at 802-951-4001, or at Sharon.Mallory@vermont.gov.

Consent:

If you say “I agree,” you are indicating that you have understood the preceding information and agree to be interviewed as part of this evaluation project.

Do you agree?

Before we begin, do you have any questions?

OK, let’s begin!

QUESTIONS

1. To start, I’d like to learn about how you came to be connected with Kindred Connections?
 - a. How did you hear about Kindred Connections? Who connected you with Kindred Connections?
 - b. How long ago did you receive your diagnosis?
 - c. How long have you been receiving support through Kindred Connections?
 - d. What kind of support were you looking for when you connected with Kindred Connections? Has this changed over time?
2. Please describe the type of support you have received from Kindred Connections volunteers?
Probe: Emotional support, support with daily living activities, transportation to an appointment?
3. Do you have any other sources of support? What are they?
 - a. What are the needs that Kindred Connections meets that is not met by your other sources of support?
 - b. Are you involved in any other cancer survivor support group in your community? Please describe.
4. I’d like to learn more about the Kindred Connections volunteers you have been connected with.
 - a. How many volunteers have you connected with as a Kindred Connections participant?
 - b. Has it been the same person you connect with over time or has it changed? Why?
 - c. How were you matched with your volunteer(s)?
 - d. How frequent would you say your conversations with KC volunteers are?
 - e. Do the volunteers serve different purposes depending on the type of support you have needed?
5. Thinking back on your connections with your KC volunteer(s), in general:
 - a. What type of support was provided? (Emotional, functional)
 - b. How was it provided? (phone, email, in-person)
 - c. Was the support helpful? Why/why not?
 - d. What would have made it more helpful for you?
6. In general, what has been the most beneficial support you have received through your connection with a Kindred Connection volunteer?
 - a. Why and how was it most beneficial to you?
 - b. What does this support mean to you? What has it done for you?
 - i. Can you describe with one word or phrase?
 - c. What aspects in your quality of life have improved by being connected with a KC volunteer?
 - d. Have you thought about/are you interested in becoming a KC volunteer, yourself?
7. Tell me about a time when the support provided was not that helpful?
 - a. Why and how was it not helpful?
 - b. What would have made it more helpful?

8. We just discussed what has been helpful and what has not been that helpful. How would you rate your overall satisfaction with Kindred Connections on a scale of 1-5, 1 being *not satisfied* and 5 being *very satisfied*?
9. We know there is always room for improvement. In general, how can Kindred Connections serve its network of cancer survivors and caregivers in Vermont better?
Probe: Training and support of its volunteers? Coordination of events? Communication of programs, services and events?



Department of Health
Agency of Human Services



We'd like to hear about your experience as a Kindred Connections Participant!

The Vermont Department of Health Comprehensive Cancer Control Program has contracted with JSI Research and Training Institute, Inc. (JSI) to provide evaluation services in order to understand how participation in Kindred Connections improves quality of life for participants and its members.

JSI will be conducting **interviews with cancer survivors and caregivers** around Vermont who have interacted with Kindred Connections volunteers. The purpose of the interviews is to learn about interactions between Kindred Connections participants and volunteers; the types of support offered through the connections, what has been most beneficial and what could be done to improve the cancer survivor peer support program through Kindred Connections.

Interviews will be conducted over the phone and will take approximately 40 minutes. Interview participants will receive a \$30 grocery store gift card as a token of appreciation for their time.

There will not be any representatives of the Vermont Cancer Survivor Network or Kindred Connections leadership, or representatives from the Health Department on the interview, and your comments will not be linked to your name.

Interviews will be currently being scheduled. If you would like to participate, please contact Jocelyn Chu, Project Manager at JSI who will follow up with you. She will ask some initial questions to make sure a diverse group of cancer survivors are interviewed for this project.

Jocelyn Chu, Project Manager
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Telephone: 617-482-9485