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Evaluation of the Leukemia & Lymphoma Society (LLS)
Myeloma Link Pilot Program

August 2018

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The National Black Church Initiative

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I. Background

The Leukemia & Lymphoma Society (LLS) is at the forefront in the fight to cure cancer. Dedicated to helping blood cancer patients through advancements in research, increased access to treatment and finding cures, LLS is the world's largest non-profit exclusively focused on creating a world free of blood cancers. The purpose of the Myeloma Link Pilot Program was to implement a church-based initiative in black communities, particularly low-income communities, in an effort to: 1) heighten awareness of myeloma; 2) increase knowledge about the disease and treatment; 3) provide information and resources that will empower patients to seek novel treatments and enroll in clinical trials in a timely manner, and 4) encourage patients and caregivers to use a new, sustainable support infrastructure. Myeloma Link pilot activities were delivered in Atlanta, GA and Washington, D.C. The National Black Church Initiative played a key role in this pilot.

The National Black Church Initiative (NBCI) is a coalition of 34,000 African-American and Latino churches working to eradicate racial disparities in healthcare, technology, education, housing, and the environment. NBCI's mission is to provide critical wellness information to all of its members, congregants, churches and the public. The National Black Church Initiative's methodology is utilizing faith and sound health science.

The National Black Church Initiative's purpose is to partner with major organizations and officials whose main mission is to reduce racial disparities in the variety of areas cited above. NBCI offers faith-based, out-of-the-box and cutting-edge solutions to stubborn economic and social issues. NBCI's programs are governed by credible statistical analysis, science-based strategies and techniques, and methods that work.

The National Black Church Initiative (NBCI) played an essential role in the pilot. NBCI with its vast church connection identified all of the participating churches, coordinated all the education in the churches. They also identified key health personnel through its volunteer health corps, under its health emergency declaration health model (HED). NBCI also provided all of the statistical data and the distribution of over 150,000 pieces of literature, in Washington, D.C. and Atlanta. It impacted through this pilot over 1 million African Americans, through the NBCI faith-based initiative.

The Myeloma Link pilot activities, which were implemented from March, 2017 through May, 2018, focused on the general populations of Atlanta and D.C. as well as members of key churches, interested community members and myeloma patients and caregivers. These populations were reached with a variety of activities as described below and shown in Figure 1.

Myeloma Link Pilot Activities

General D.C. and Atlanta Populations

- Radio PSAs
- Awareness Tabling at Community events

Church Members in D.C. and Atlanta

- *Myeloma Sunday Events* - A brief, myeloma-focused “health sermon” delivered during Sunday worship at select churches
- *Fellowship Hours* - A time after the sermon when LLS staff and ambassadors provide information about LLS resources

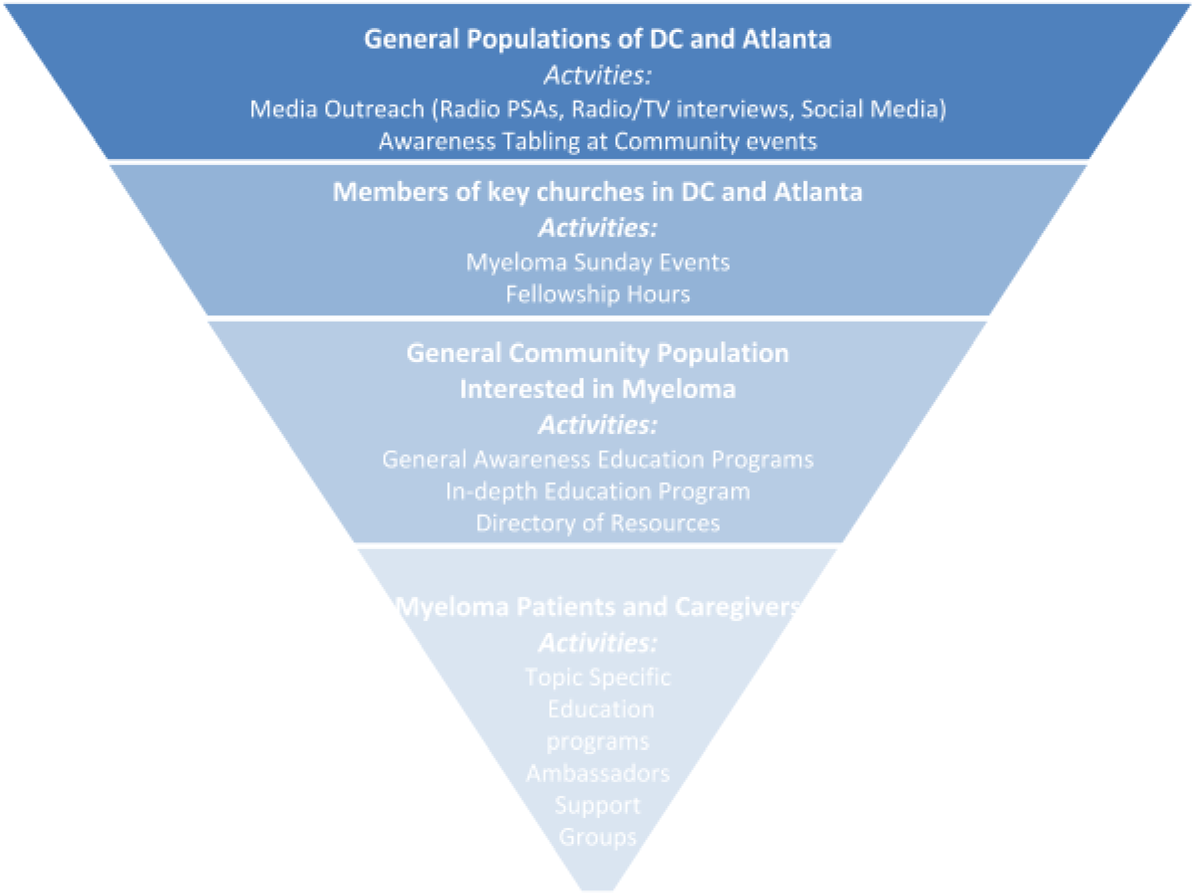
General Community Population Interested in Myeloma

- *General Awareness Programs* - Education program designed to raise awareness about myeloma and LLS resources
- *In-depth Education Program* - An in-depth, myeloma 101 education program
- *Directory of Resources and Cancer Centers*

Myeloma Patients and/or Caregivers

- *Topic Specific Education Programs* - Two education programs focused on treatment and survivorship (both in D.C.)
- *Myeloma Ambassadors* - Patients and/or caregivers trained to reach out with support and information
- *Support Group Needs Assessment* – An assessment of support groups in the Atlanta and D.C. areas to determine the need for new support groups

Figure 1 Myeloma Link Activities



Shattuck and Associates (S&A), a program planning and evaluation firm, was contracted by LLS to conduct an evaluation of the LLS Myeloma Link Pilot Program. S&A, in collaboration with LLS, conducted surveys to evaluate Myeloma Link activities including: Myeloma Sundays, Fellowship Hours, In-depth and Awareness Education Programs. In addition, S&A conducted in-depth interviews with project staff, Myeloma Ambassadors, and participants who were involved with planning and delivering Myeloma Link activities. Finally, S&A supported LLS in tracking Myeloma Link events and community interactions as well as media outreach. This report presents the findings from this evaluation.

II. Methodology

This section details the methodology used in the evaluation including evaluation questions, tool development, data collection and data analysis.

Evaluation Questions

A theory of change model was used as a basis for planning the evaluation (Appendix A). The theory of change demonstrates the connection between Myeloma Link activities, the target population, and the intended short and long-term outcomes. A plan was developed to evaluate the pilot project based on this theory of change and evaluation questions were developed through an iterative process with LLS staff. The evaluation questions were broken down into process and outcome questions and were designed to help LLS evaluate the activities and to better understand how findings from the pilot project can be used to improve and sustain the project in the future. The evaluation questions included:

Process Evaluation Questions

1. What are the characteristics of the participants of the LLS Myeloma Link Pilot Program?
2. How do LLS Myeloma Link Project participants interact with the LLS Myeloma Link Pilot Program?
3. What are the LLS Myeloma Link Project participants' experiences with the LLS Myeloma Link Pilot Program?
4. What do participants suggest for sustaining and improving the LLS Myeloma Link Pilot Program in the future?

Outcome Evaluation Questions

1. As a result of participating in the LLS Myeloma Link Pilot Program, to what extent do participants increase awareness of available resources?
2. As a result of participating in the LLS Myeloma Link Pilot Program, to what extent do participants increase awareness and knowledge of myeloma, diagnosis and treatment?
3. As a result of participating in the LLS Myeloma Link Pilot Program to what extent do members experience positive changes in their social support?
4. As result of participating in the LLS Myeloma Link Pilot Program, do participants increase skills/behavior to help them navigate the treatment landscape more effectively cope with their disease?

Data Collection and Analysis

Data to answer the evaluation questions were collected using paper and pencil assessments, through internal activity tracking coversheets and Salesforce. Additional open-ended data was collected. Surveys, a tracking cover sheet and interview guides for each interview group were developed in collaboration with LLS staff (See Appendices B-K). Participants of the Myeloma Sundays, Fellowship Hours, and Education Programs

(Awareness: Two Topic Specific and one In-depth) were asked to complete exit surveys at the end of the program. In the case of the one in-depth education program, the participants were asked to complete both a pre and post-survey. Tracking of outreach events was conducted through the use of event cover sheets completed by program coordinators. Outreach activities and two-way interactions with churches and other organizations were tracked using Salesforce. Ambassadors were asked to complete a short survey to evaluate their First Connection Training. In addition, LLS conducted a support group needs assessment and implemented and tracked several media outreach activities.

For in-depth interviews, the LLS team provided a list of potential staff members, ambassadors and community support participants. Community support participants (CSPs) were individuals who played a role in delivering or planning Myeloma Link activities. Interview participants included four staff members, three ambassadors and 10 CSPs. Interviews were conducted between March and June 2018 and lasted an average of 30 minutes, ranging from 15 to 49 minutes.

As indicated in Table 1 below, a total of 530 participants responded to the Myeloma Sunday Surveys (96 in D.C., 434 in ATL). Fifty-five 55 participants completed the Fellowship Hour Survey in Atlanta. Regarding Topic Specific Education Programs, 20 participants completed the Therapies Survey, while 16 completed the Survivorship Survey. A total of 221 participants completed an Awareness Education Program Survey (23 in D.C., 198 ATL). In-Depth Education Programs utilized a pre and post survey and generated 24 pre surveys and 20 post surveys, with 16 participants completing both.

Table 1. Myeloma Link Activities and Corresponding Methods

Myeloma Link Activity	Data Collection Method	N
Myeloma Sunday Events	Sermon Survey	530 (96, D.C. & 434, ATL)
Fellowship Hour	Fellowship Hour Survey	55 (ATL only)
Topic Specific Education Programs	Topic Specific Survey	36 (D.C. only)
General Awareness Education Programs	Awareness Survey*	221 (23 in D.C., 198 ATL),
In-depth Myeloma 101 Education Program	Pre-Post Survey	Approx. 24 completed either pre or post or both**
Interviews	Interview Guide	17 (4 LLS Staff, 3 Ambassadors, 10 CSP)
Myeloma Ambassadors	First Connection Training Survey	5 (3 D.C., 2 ATL)
Support Group Needs Assessment	Interviews, Surveys, Map	Total of 15 phone and electronic surveys
Media	LLS Tracking of events	TV and radio interviews, PSAs

*One General Awareness Program administered the in-depth education program surveys, only post-survey data is reported

** Activities that took place after May 15th might not be captured in this analysis

Survey items were analyzed using descriptive statistics, including frequencies, percentages, and means. Interview responses were first examined to identify themes and then were coded by theme. Findings are combined and summarized in the section below. A summary of detailed results with data tables is included in Appendix L.

III. Key Highlights

The following are topline highlights of the evaluation results. Please see the Detailed Findings section for a deeper exploration of the results.

Process Evaluation

Characteristics of the participants of the LLS Myeloma Link Project

Characteristics of participants were collected through demographic questions and questions about participants' current awareness of myeloma and patient status.

- Survey findings showed that overall, most participants in the Myeloma Sunday and In-depth Education Program were:
    - Not myeloma patients or caregivers
    - Older than 55
    - Female
    - Black or African American
- Participants in the Topic-Specific Educations Programs were more likely to be:
    - Cancer patients or caregivers (60%) in the Therapies Education Program and 6% in the Survivorship reported having myeloma
    - More even split between male and female participants
- Ambassadors
    - Four of five ambassadors were female and reported were myeloma patients or caregivers
    - Five volunteers participated in the LLS First Connection Training. Three of them became Myeloma Link ambassadors in D.C. and two in Atlanta.
    - Three of the five ambassadors were patients or survivors.
- Interviewees
    - Two supervisory staff
    - Two program coordinators
    - Three ambassadors who were volunteers with LLS before and patients or caregivers.
    - Roughly half of the CSPs worked in the health or social work fields.

Participants' interaction with the Myeloma Link activities

To determine interactions of participants with Myeloma Link activities, information was collected to track participation in various Myeloma Link events. In addition, data was collected to gauge the extent to which participants continue to participate in outreach activities and become engaged with LLS.

- The Myeloma Link project included a total of 26 Myeloma Sunday Sermons (17 in Atlanta, 9 in D.C.) and 16 education programs (12 in Atlanta, 4 in D.C.). In addition, several other types of outreach activities, including media events, took place in both cities reaching over 4000 people in the target population.

Participants’ experiences with the outreach activities

To measure participants’ experiences with Myeloma Link, information was collected to assess general participant satisfaction, the information presented, feedback about formatting, and usefulness and value of Myeloma Link activities.

Satisfaction

- Overall, survey participants expressed satisfaction with Myeloma Link events and activities.
- Myeloma Link participants were generally engaged in the activities, especially participants of the education programs.
- All of the interviewees felt that participants were generally satisfied with the outreach activities including Sunday Sermons, Fellowship Hours, Education Programs and other outreach events. In addition, CSPs expressed personal satisfaction with their involvement in Myeloma Link.

Value and usefulness

- All staff felt that the Myeloma Link activities provided value to participants in terms of raising awareness and being proactive in their health care; they felt the education programs were particularly valuable for patients.
- While ambassadors serve as an important link to the myeloma community, there is a need to clarify their role and balance their workload.
- While some churches were open to the Myeloma Sundays, other churches were less receptive to incorporating health messages into Sunday worship services.

Participants’, Staff and Ambassadors Suggestions for Sustaining and Improving Myeloma Link in the future

Interviewees were asked to provide recommendations for improving the LLS Myeloma Link Program in the future. In addition, the interviewees were asked to provide recommendations related to strengthening partnerships and reaching Black and African American patients with myeloma. Staff members also provided suggestions for improving the role of staff members and volunteers and the process of data collection.

- Most suggestions related to strengthening partnerships focused on relationship building and networking with organizations beyond churches, improved program promotion/public relations for LLS and Myeloma Link, and increasing community presence.
- Interviewees provided suggestions related to reaching Black and African American patients in addition to the current approach of targeting churches. Recommendations centered around connecting with health care providers and other community organizations as well as increasing media activities and connection with Black stakeholders in the community.
- Staff recommendations focused on expanding the project beyond churches, delivering more education programs, re-examining the volunteer structure and creating outreach tools so the project can be more self-driven.
- Ambassadors recommended utilizing ambassadors for participant recruitment, and improving system of communication with churches before the Myeloma Sundays.

- CSPs suggested improving and updating educational materials and making changes to the Myeloma Sunday Sermon (e.g. offering evening session, increase the length of the health sermon).

Outcome Evaluation

To determine outcomes that resulted from participation in Myeloma Link, questions were asked about changes in participants' awareness of available resources, awareness and knowledge of myeloma, diagnosis and treatment. CSPs and ambassador were asked to provide feedback about increasing social support and disease management skills/behaviors.

- Overall, Myeloma Link Program participants reported increased awareness of LLS resources. Likewise, participants in the in-depth program showed knowledge gains related to myeloma. Based on feedback and their own observations, ambassadors and CSPs felt that participants experienced an increase in awareness and knowledge of LLS resources and myeloma, particularly as a result of the education programs. All CSPs reported a significant increase in their own knowledge and awareness of myeloma and diagnosis, treatment and resources for persons with myeloma.
- Suggestions for improving social support among Black and African-American myeloma patients/caregivers in the community included the promotion and dissemination of LLS resources, connection of patients with health care providers, social workers, and other resources including support groups at local churches.
- Suggestions for how to help myeloma patients increase skills/behaviors to navigate treatment to more effectively cope with their disease included continued communication, education and empowerment so patients can reach out to health professionals and other patients for the appropriate support.

IV. Detailed Findings

Process Findings

This section presents the findings related to the process evaluation questions. Specifically, findings related to the characteristics of the participants of Myeloma Link, how the program participants interact with the Myeloma Link outreach program, the participants' experiences with the project, and suggestions for sustaining and improving the LLS project in the future are presented.

Characteristics of Program Participants

Myeloma Link, Education Program and Fellowship Participants

Characteristics of the survey participants of the Myeloma Sundays and Education Programs are presented in Table 2. Overall, most participants in the Myeloma Sunday and Myeloma 101 Education Program were not myeloma patients or caregivers, older than 55, female, Black or African American. More of the participants in the topic-specific educations programs were cancer patients or caregivers, with over 60% of the participants in the Therapies Education Program and 6% in the Survivorship reported having myeloma. There was also a more even split between male and female respondents who participated in the topic-specific education programs. See Appendix L for detailed demographic information. In Atlanta, 55 Fellowship Hour Survey respondents were collected. Most of the respondents (77%) reported not having myeloma but an interest in learning more about it. In addition, majority of them either reported wanting to talk with an Information Specialist about myeloma and resources that may help (28%) or reported in interest in attending a myeloma education program or support group (38%). Only 16% of the respondents expressed interest in connecting with the Myeloma Link program to another community group that they know.

Table 2 Demographic Characteristics for Participants of Myeloma Sundays and Education Programs

Myeloma Sunday & Myeloma 101 Education Program Participants	Topic-specific Education Programs	Fellowship Hours
● Not Patients or Caregivers ● Older than 55 ● More Female ● Black or African American*	● Patients or caregivers ● Male and Female ● Older than 55 ● Black or African American or White/Caucasian	● Most did not have myeloma but interested in learning more ● Some wanted to talk to Information Specialist ● Some interest in attending education program or support group

*Race was not asked on the Myeloma Sunday survey

Characteristics of Ambassadors

Five volunteers participated in a two-part ambassador training between October 2017 and January 2018. This program trains patients/caregivers to be peer volunteers and connect with other blood cancer patients. Three of them became Myeloma Link ambassadors in D.C. and two in Atlanta. Three of the five ambassadors were patients or survivors. Four of the five ambassadors were female and reported a patient's diagnosis of myeloma.

Characteristics of Interview Participants

Interview participants included 4 staff members, 3 ambassadors and 10 CSPs.

- Two staff played supervisory roles, and the other two were program coordinators doing more "ground work."
- The three ambassador interviewees were volunteers with LLS before and patients or caregivers. One was an ambassador since the inception of the Myeloma Link Pilot Project, and the other two had been ambassadors for 2-5 months.
- Half of the CSPs knew nothing about myeloma and had no experience with LLS before Myeloma Link. Most of the others were in the nursing field and had

experience working with myeloma patients. One CSP was a social worker that led a support group at a local cancer center.

Participants' interaction with the Myeloma Link activities

Participation in Myeloma Link outreach activities

The Myeloma Link project included a total of 26 Myeloma Sunday Sermons (17 in Atlanta, 9 in D.C.) and 16 education programs (12 in Atlanta, 4 in D.C.). Education programs included 1 in-depth, 2 topic-specific and 13 awareness programs. In addition, post-service Fellowship Hours occurred after many of the Myeloma Sundays, and several other types of outreach activities took place in both cities reaching over 4000 people in the target population.

In terms of other community interactions (i.e. calls, email, meeting, online chats, or other) reported in Salesforce, an estimated 123 and 49 interactions were reported in Atlanta and D.C., respectively. Many of the reported interactions resulted in various types of outreach including General Community Awareness (n=128), Presentation (non-LLS) (n=23), Tabling at Health Fairs (n=18), and Tabling at Program/Event outreach activities (non-LLS; n=6) and two-way interactions with churches and other organizations were tracked using Salesforce. Salesforce data output showed a 48% increase in IRC inquiries specific to myeloma in Atlanta between pre and post the Myeloma Link Pilot Program. This far out-paced the 17% increase in IRC inquiries seen nationally.

Over 75 coversheets were completed and used to track details related to implementation of activities. According to cover sheet data, over 4000 people listened/attended/stopped by these activities in both D.C. and Atlanta in 2017 and 2018. While the churches involved in Myeloma Link ranged in size, over 60% of respondents reported small congregations fewer than 50 members (26%) or 50 to 100 members (42%). In addition, most churches (80%) were Baptist. Cover sheets also captured open-ended feedback about program implementation. Limitations of the cover sheets and Salesforce database should be noted as these systems did not capture every Myeloma Link activity or event. While these tracking systems provide estimates of activities and interactions with participants, it is likely that the number of activities is underestimated.

Media Outreach

Media outreach was intended to raise general awareness. Myeloma Link in D.C. partnered with Radio One, and ran PSAs and a radio interviews, one with the Myeloma Link coordinator and two others with a myeloma survivor/ambassador. In addition, LLS was highly visible at a large gospel music concert and was able to raise awareness about myeloma and LLS resources through social media posts, radio activity and a presentation by a myeloma survivor who is a reverend in the area and became a trained Myeloma Link ambassador. As a result of this media activity, LLS documented an increase in hits to the Myeloma Link website in the month of October, following media efforts. Additional media outreach including TV interviews with two LLS volunteers and staff occurred in March and September 2017. In 2018, Myeloma Link was featured in an Atlanta television segment.

Interviewees' Interactions with Myeloma Link

Interviewees described their involvement in a variety of Myeloma Link activities. Ambassadors made counseling calls and other outreach activities (e.g. education, recruitment, promotion), and participated in media events. CSPs played various roles in Myeloma Link including planning events, disseminating educational information, participating in media events (e.g. promotional videos), and leading in-house church initiatives. Specific activities mentioned by staff, ambassadors and CSPs are presented in Appendix M.

Participants' Engagement with Myeloma Link Activities

According to feedback provided on the cover sheets as well as feedback provided by the interviewees, Myeloma Link participants were generally engaged in the pilot activities. Interviewees emphasized high levels of engagement among of participants who attended education programs. Of the cover sheet respondents who answered the engagement question, more than half reported that most participants were "mostly" to "completely" engaged with the activities.

In general, interviewees felt that participants seemed to be engaged in the Myeloma Sundays that they attended. Staff felt that the fellowship hours worked well as an avenue for delivering more "in-depth information" (e.g. finances, disease, resources). Some people seemed receptive and wanted more information and this activity provided an opportunity to ask more about Myeloma Link.

More than half of the CSPs attended different Education Programs and observed participant engagement and perceived that participants had a clear understanding of the information presented. A few CSPs noted that the presenters did a great job engaging participants, helping them feel comfortable and leading helpful question and answer sessions. CSPs described participant engagement in a few other specific activities (e.g. the Workshop, Family Fun Day, Luncheon).

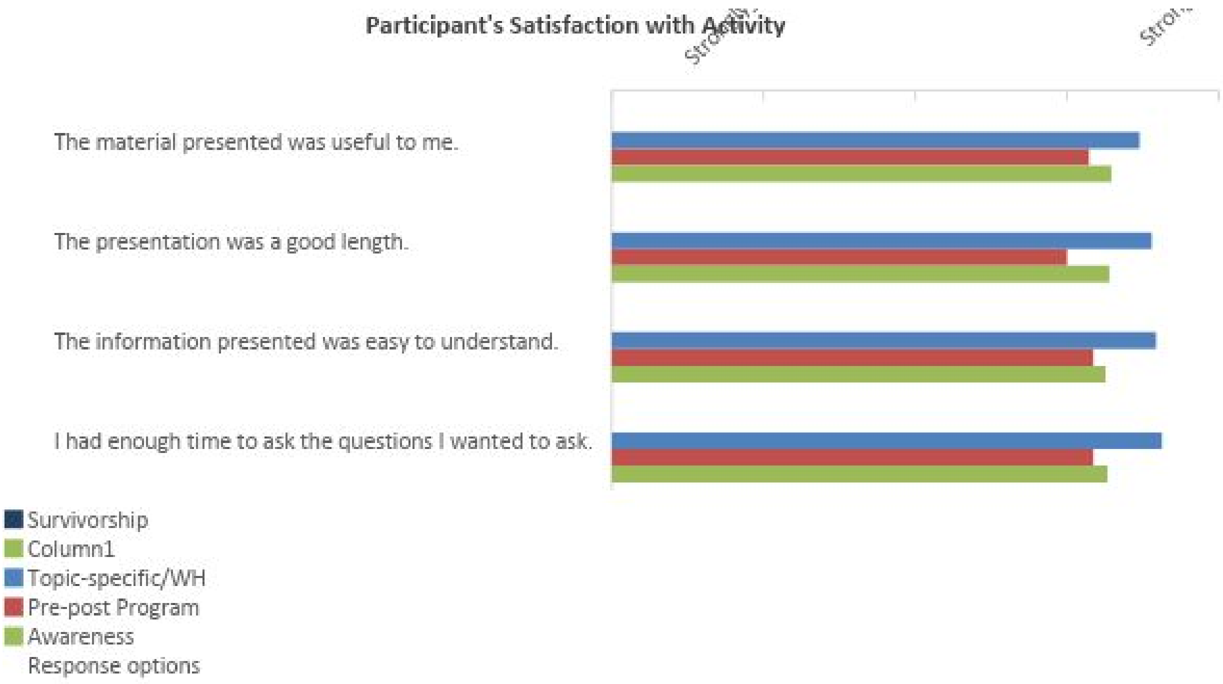
> *. . .good engagement and questions and people saying verbally good to get the information, people had great questions, personal connections.*
>
> *Participants in the education program delivered just to patients and caregivers were grateful for the knowledge, very interactive and participatory*

Participants’ experiences with Myeloma Link activities

Participants’ Satisfaction with Education Programs

Most survey respondents were satisfied with all aspects of the Education Programs including material presented, length of presentation, ease of understanding information and time to ask questions (Figure 2).

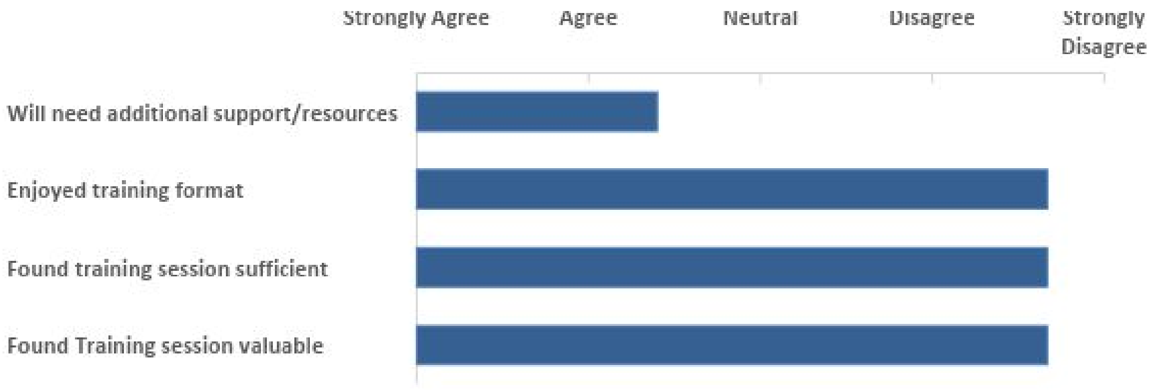
Figure 2 Participants’ satisfaction with Myeloma Sunday and Education Programs



Ambassador Satisfaction with First Connection Training

All five ambassadors reported, “yes” that as a result of the training, they felt prepared to speak with newly diagnosed patients/caregivers. In addition, most of the ambassadors “agreed” to “strongly agreed” that the training was valuable, sufficient and that they enjoyed the format. Overall, they disagreed that they would need additional support before completing a First Connection (Figure 3). In addition, ambassadors provided several positive comments about their role-play experience and about the training overall (Appendix L). The ambassadors described the training as “*clear, easy to follow, visually appealing, and well-organized*” and that it provided helpful information for moving forward. One ambassador expressed appreciation and felt part of the LLS community after completing the training.

Figure 3 Ambassadors' satisfaction



*Some data missing or respondent misunderstood scale so left missing

All of the interviewees felt that participants were generally satisfied with the outreach activities, including Sunday Sermons, Fellowship Hours, Education Programs and other outreach events. In addition, CSPs expressed their own satisfaction with their involvement in Myeloma Link. Specifically, satisfaction with the education programs was highlighted. Satisfaction with the success of tabling events/health fairs was inconsistent.

They were satisfied … excited to get the information and have few things clarified; a lot of them have never heard of myeloma; good for them to hear about the information…know that something out there for them in case they do develop myeloma

Some staff felt that the satisfaction with the Fellowship Fours was harder to gauge because it was more of an extension of the Sunday Sermon than a separate piece, and, thus, most feedback they received related to the sermon. But other staff felt that the Fellowship Hour worked well as an avenue for delivering more "in-depth" information describing that participant were receptive and wanted more information.

Interviewees felt that the educations programs were well received based on the amount of discussion and Q&A that occurred during the programs. They described how some participants voiced satisfaction and appreciation as well as eagerness for more information. Less feedback was received from participants who attended awareness activities, but interviewees felt they were helpful in reaching underserved populations and seniors and raising awareness about myeloma. One interviewee mentioned that satisfaction with health fairs was "hit or miss" depending on the health fair.

It was suggested that health fairs require an assessment of which ones will "*get a lot of traffic*" ahead of time but some have been "*great connectors*" for the project.

> *Provided great opportunity to provide additional detailed information and connect with someone who wants more info and connect with an ambassador*

> *The participants were informed enlightened, educated and grateful for the information.*

Participants' understanding of the information presented in the activities

Overall staff interviewees felt that participants understood the information presented about myeloma, particularly the education program participants. However, a couple of interviewees noted the challenge of presenting the information under the title "Myeloma Sunday" and during a church service where participants might "*zone out…until the actual preaching*," and, thus, misunderstand or missed important information. Staff provided a few suggestions for clarifying information presented in activities including simplifying information by creating user-friendly tools such as placards or bookmarks with key information and using professional quality videos as seen in some of the churches. In the future, developing Sunday Sermons in closer partnership with churches at the grassroots level may prove useful.

Participants' satisfaction with the format of the activities

Overall staff interviewees reported receiving limited but positive feedback about the format of the activities. It was noted that they did not receive as much feedback, in terms of format, about the Myeloma Sundays and it was "very different from church to church." It was noted that the participants seemed to like the educational pieces and programs versus the sermon health message. One respondent, for example, received positive feedback about providing messages specifically for caregivers and patients, serving refreshments, and using speakers that were really prepared to answer questions and have time for discussion. Another emphasized that participants provided positive feedback about one education program delivered at a church complimenting the style of the speaker (i.e. *using a conversational and interactive approach*). In addition, participants provided positive feedback about the format of the Therapies education program because they were able to ask questions throughout and speakers were comfortable and knowledgeable.

A couple CSPs received feedback with regards to the format of activities and described that the participants enjoyed the simple and easy to follow format. One CSP stated that the workshop format/model was the <u>best</u> because there was "so much dialogue" and audience participation in that type of activity. Also, one CSP noted only moderate engagement at the Fellowship Hour activity after the lengthy 2-hour long church service.

Challenges Faced by Staff, Ambassadors and CSP in terms of scheduling and delivering outreach activities

Interviewees were asked to cite any challenges they faced in terms of scheduling and delivering outreach activities. All three groups described some challenges related to logistics of scheduling events. Staff emphasized the challenge of asking churches to deliver health education information during a time of worship (Table 3).

Table 3 Challenges sited by Interviewees

Main Challenges Scheduling and Delivering Outreach Activities	Staff
	● Communication: Making the right connections with key players ● Scheduling Logistics ● Asking churches to deliver health message during sermon, “hard sell” ● Consider using a patient, not a professional, to deliver the health message
	Ambassadors
	● Understanding and maximizing their own role ● Personal challenges ● Follow-up with churches
	CSP
	● Logistics in terms of scheduling events ● Time limitations related to event preparation and presentation time for information presented as part of the Sunday Sermon

Value of the activities of LLS Myeloma Link Activities – Staff and Ambassadors Perspectives

Based on observations, all staff felt that the Myeloma Link activities provided value to participants in terms of raising awareness and being proactive in their health care; the education programs were particularly valuable for patients**.** On the other hand, the value of the Sunday Sermons was not as clear. Several felt that it was hard to understand the real value of the information unless someone had a personal connection to myeloma despite the fact that most people were polite and grateful for the information. CSPs also found value in their own personal involvement in Myeloma Link. One emphasized that as the health and wellness coordinator for her church, it was advantageous to connect with LLS for future questions stating that *“it opens doors for people to ask questions.”*

Since Myeloma disproportionately affects Black people it was powerful to raise awareness in the Black community

Very, very important and the impact was huge on the population

All of the interviewees believed that the ambassador role in the Myeloma Link Project holds significant importance. Overall staff provided positive feedback

An ambassador is the only person that can do it well. We are not paid and do not have any incentive except for the fact that (our work) is life changing and personal. And that is the truth!

about the use of ambassadors, but a few mentioned challenges including training, availability, health-related limitations and balance of workload. One highlighted the importance of ambassadors because they add a "*personal touch*" and a "*direct connection*" noting that ambassadors were a "*link back to the myeloma community because they can spread the word and bring more ambassadors.*"

Another emphasized the need to clarify the role of ambassadors, a role that was not very clear in the beginning of the project. It was noted that their role can be community outreach volunteers who go out and build the relationships and help support patients and caregivers. One emphasized the need to balance between growing the number of volunteers and expanding their role with finding the adequate amount of work for them to do. While one ambassador felt that she came to the project too late to maximize her potential as an ambassador, the others felt that the role of ambassador would be useful in bringing groups together and relating to survivors and caregivers as someone who experienced myleoma.

Ambassadors themselves noted positive aspects of utilizing ambassadors and offered useful recommendations for improving the program in the future. Overall, they felt that the training process was exceptional, that Myeloma Link staff were readily available and responsive to questions and successfully supplied ambassadors with necessary resources. To maximize the use of ambassadors, they recommended explicitly defining ambassadors' roles and duties and doing more role-playing in training to keep ambassadors up to date on outreach and education skills and current medical research.

Participants', Staff and Ambassadors Suggestions for Sustaining and Improving Myeloma Link in the future

This section presents recommendations related to sustaining and improving the Myeloma Link Project. Interviewees described recommendations related to strengthening partnerships and collaboration with local churches, community organizations, and other partner organizations to improve the program as well as suggestions on how to best reach Black and African American myeloma patients. Staff members also provided suggestions for improving their current role, the role of other staff members and volunteers and feedback related to measuring, collecting and reporting data related to the implementation of outreach activities.

Overall Recommendations for improving Myeloma Link

Interviewees provided important recommendations for improving the Myeloma Link project in the future. Staff recommendations focused on expanding the project beyond churches, delivering more education programs, re-examining the volunteer structure and creating tools so the project can be more self-driven. Ambassadors recommended utilizing ambassadors for participant recruitment and improving systems of communication with churches before the Myeloma Sundays. CSPs suggested improving and updating educational materials, increasing the length of the health sermon and offering opportunities for evening activities. Both Ambassadors and CSPs recommended increasing the use of social media for promotion. Details related to these overarching recommendations are summarized below (Table 4).

Table 4 Overall recommendations for Improving Myeloma Link

Staff

- Expand project beyond churches to reach underserved population and patients: Senior centers, clinics, 100 Black Men, Baltimore based AAWAC, cancer centers, community health fairs, senior center professional societies, AA nurses, fraternity and alumni
- Allow flexibility and time to build relationships
- Understand the "word of mouth" nature of project
- Build and expand the role of volunteers and volunteer support to help with awareness and outreach development
- Create tools for volunteers and churches so the project is more "self-driven"
  - Create a program toolkit for volunteers to use
  - Create messaging to be used in church bulletins
- Focus on delivering more education programs and delivering messages in church after the service as opposed to during the service

> *A lot [of churches] would watch movies about announcements, programs, upcoming events, videos they show about church events, so if we did something like that that fits with announcements, a little more exciting than a person speaking only so much you can do.*

> *Being open to understanding this is a word of mouth success not a top down success…that is how we have experienced most success…understand pace might be slower and takes time to build relationships…being open and flexible…churches have own idea how to get information out.*

Ambassadors

- Utilizing Ambassadors' personal relationships to recruit more churches
- Communicate effectively with church staff to present the activity beforehand
- Reaching out to executive assistants rather than pastors may be more effective
- Utilize social media (Facebook), church websites, streaming services to reach the community

> *I'm a baby boomer generation, but now we're churched from home. Myeloma Link will need to expand itself to infiltrate the community better. You have to use the language of the day, streaming technology.*

Community support participants

> *People want to see you invested in them – it may take attending Sunday services.*

- Improve educational materials
- Continue heavy recruitment of new churches
- Reach out to doctor's offices, cancer institutes and attend ONS Conference in D.C., community fairs, barbershops, grocery stores and festivals
- Timing: Offer workshops in the night time as well as day time; Present for 15 minutes, vs. 5-10 minutes
- Change title "Sunday Sermon" to "Ministry Moment" – It would be better received in the Black church and by pastors by not using "sermon" in the title
- Utilize social media for promotion – the seniors may not be on social media but the families are definitely on there
- Keep updating information with new research (e.g. do updated Myeloma Sunday)

Recommendations to strengthen partnerships and collaboration

Interviewees provided some important suggestions with regards to strengthening partnerships to improve the program. Most of the suggestions focused on building relationships and networking with other organizations, increasing program promotion/public relations for both LLS and the Myeloma Link Program, and creating a presence in the community (Figure 4). Respondents provided some specific and interesting ideas for potential partner organizations extending beyond churches including but not limited to Black owned businesses, health clinics, sorority/fraternity groups, senior centers, major employers, pharmacies, and the YMCA. (Appendix M).

Figure 4 Recommendations – Strengthening Partnerships

Relationship Building & Networking

[Connect with] places that community visits and trusts… get info that would be volunteer or turnkey because staff can't go to every place, continue to build relationships

Build relationships over time through word of mouth strategies as opposed to cold calls

Find ways to keep them (the priority population) connected to the LLS/ML so it doesn't feel superficial and short

Project Promotion

Better "PR" to expose other churches to the Myeloma Link project

Improve packaging (e.g. "as something really nice to send out that is compact")

GET ON THEIR WEBSITE! – Digital communication/marketing is key

Creating Presence in the community

Have presence when not pushing LLS programs and then when going out to push LLS initiative you have connections and people more likely to say yes

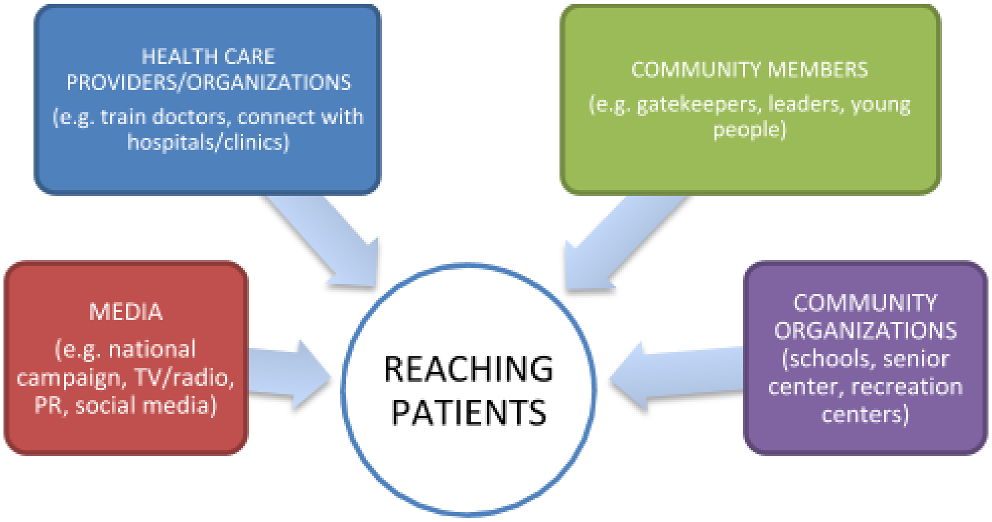
Increase presence of LLS & ML representatives need to be physically present at the churches for months to efficiently build the rapport and relationship

I don't know about just dealing with churches…can reach many people with different avenues…just get it out to the community as much as possible and not worry about if church or college but value everything the same

Suggestions on how to best reach Black and African American Myeloma patients

Interviewees provided some important suggestions on how to best reach Black and African American myeloma patients beyond churches. Overall, interviewees provided some useful ideas in terms of connecting with various groups including health and non-health organizations, increasing promotion through media activities, and connecting with the black community through key groups such as gatekeepers, leaders, young people. Figure 5 presents the overall recommendations related to reaching patients.

Figure 5 Interviewee Suggestions – Reaching Black and African American Patients



Staff Recommendations – Improving Roles of Staff/Volunteers and Data Collection

Staff interviewees were asked to provide feedback about the role of Myeloma Link staff and volunteers and the process of data collection related to the implementation of Myeloma Link activities. Suggestions for improving the role of Myeloma Link staff and volunteers to help improve and expand the project included the following: 1) Examine the role of program coordinators, giving them more independence; 2) Improve communication between program coordinators and management; 3) Expand to a new model that is more volunteer driven and reduces staff time; and 4) Clarify and balance the role of volunteers including ambassadors.

Staff also provided important feedback about measuring, collecting and reporting data related to the implementation of outreach activities. Overall, staff recommended the following: 1) Build trust among participants (e.g. explain reason for collecting data, avoid asking personal information, ask for zip code instead of home address); 2) Revisit survey distribution for the Sunday Sermons (not as easy to distribute right after church), 3) Streamline and simplify the process to keep it consistent and entered in one database;

4) Allow a place for participants to specify in what capacity they want additional information, and 5) Ask participants for suggestions on improving the program and networking to help fulfill the mission of LLS.

> *"We should make clear reason why we collect the data – if collected to fulfill the elements of the grant or if collected so we can know about myeloma…why collected needs to be articulated more to the folks because people get suspicious"*
>
> *"maybe if it is completely volunteer run there would be more for volunteers to do"*

Outcome Findings

This section presents the findings related to the outcome evaluation questions. Specifically, findings related to participants' increase in awareness of available resources; participants' increase in awareness and knowledge of myeloma, diagnosis and treatment; and, participants' change in social support are described. In addition, results related to participants' increase in skills and behaviors to help them navigate the treatment landscape and more effectively cope with their disease is briefly discussed.

Participants' increase awareness of available resources

Awareness of resources was evaluated with three different questions depending on the survey administered. Over 90% of Sunday Sermon participants reported that they knew more about LLS myeloma resources after the program. About half or more of participants in general awareness programs and the Survivorship program reported awareness of how LLS supports patients with myeloma (Figures 6 and 7). In addition, more than half of all participants in the Therapies Education Program and almost half in the In-Depth Education Program reported that they knew about LLS resources. Post-survey data showed in increase in the percentage of participants who reported awareness of resources after the In-Depth Education program for all resources (Figure 8).

Figure 6 Awareness of LLS resources – Sunday Sermon Participants

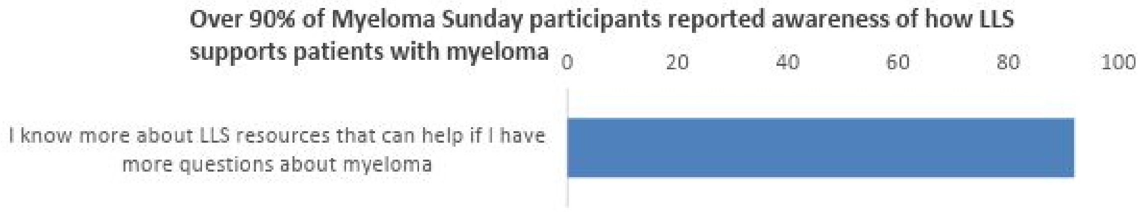


Figure 7 Awareness of LLS resources – Awareness/Topic-Specific Education Participants

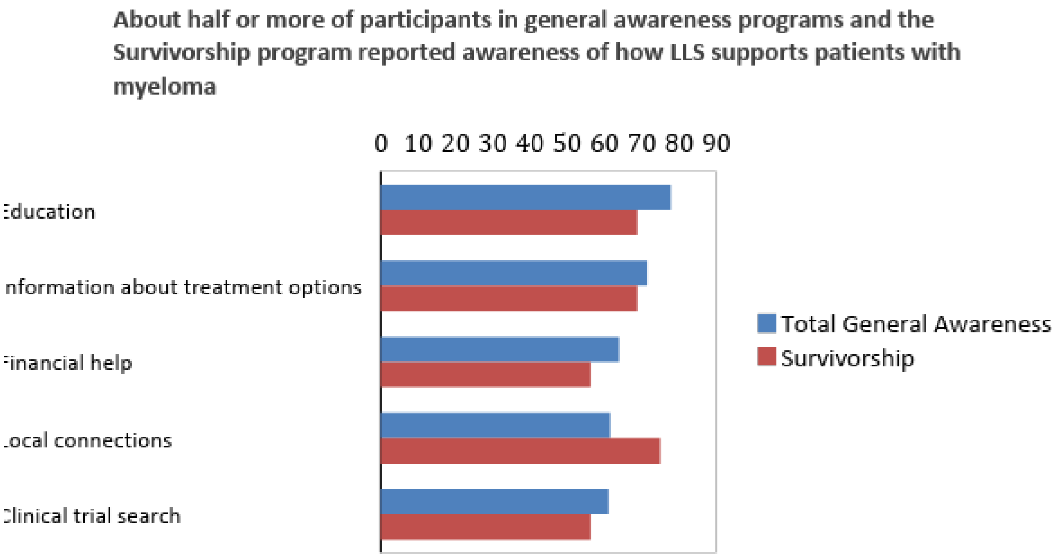
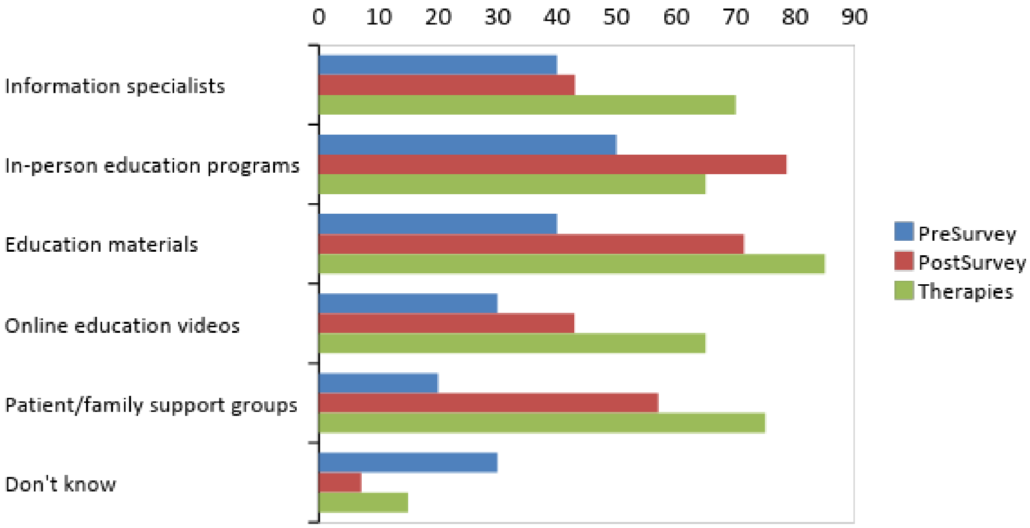


Figure 8 Awareness of resources – In-depth Education Program and Therapies Program

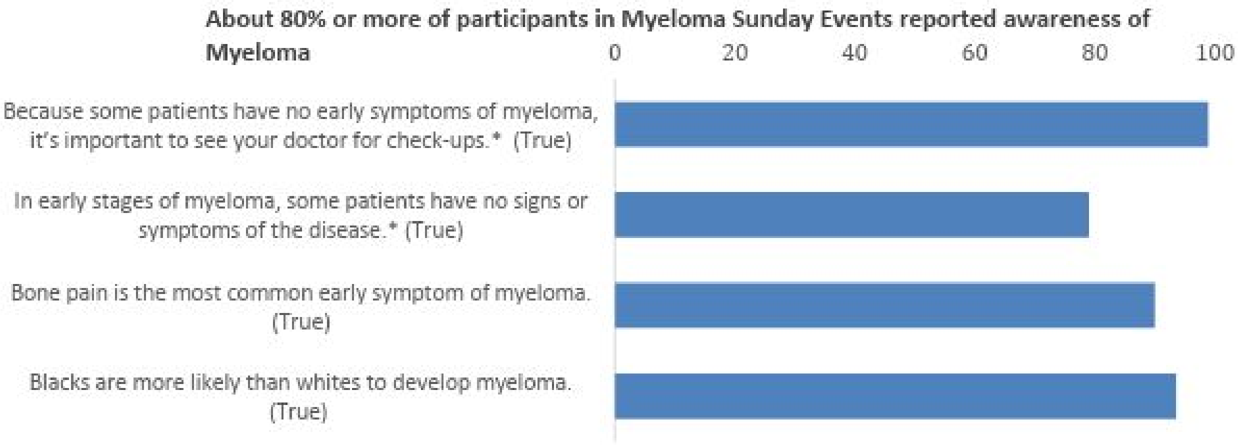


Participants' increase awareness and knowledge of myeloma, diagnosis and treatment

General Myeloma Awareness

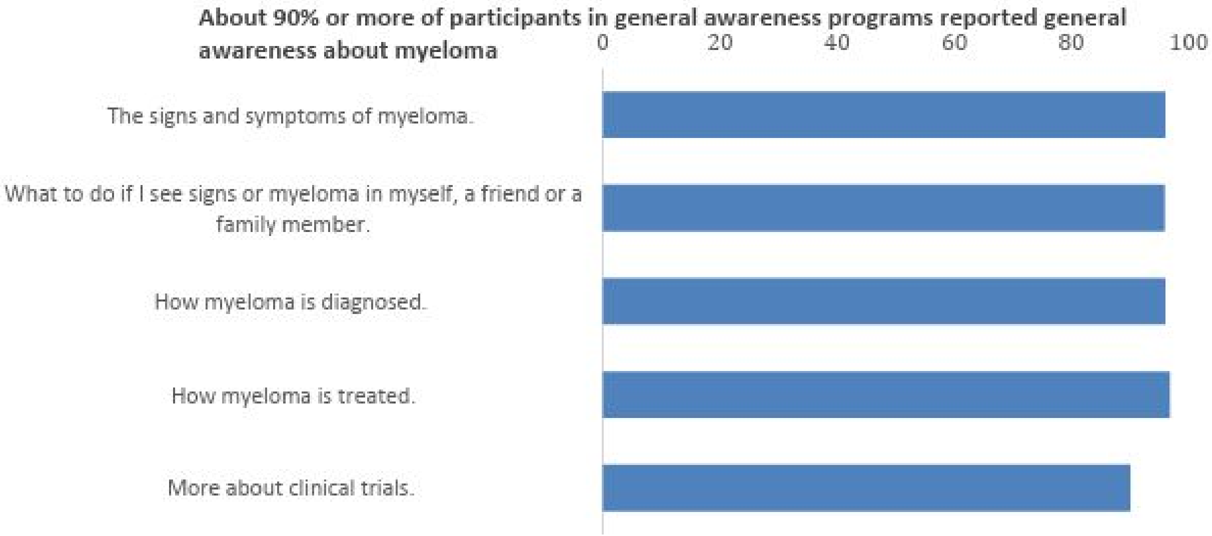
A majority Myeloma Sunday participants reported general awareness of myeloma after the Sunday event (Figure 9). Of those who responded, 90% or more of participants in the Awareness Education Programs reported general awareness of myeloma after the programs (Figure 10).

Figure 9 Awareness of Myeloma – Myeloma Sunday Participants



*The wording of this question changed – both versions are presented here.

Figure 10 Awareness of Myeloma – Awareness Education Program Participants



Education Programs – Risk Factors, General Myeloma Knowledge, and Knowledge Gains

Participants in the In-Depth Education Program generally showed knowledge gains related to myeloma. While less than half of all participants correctly knew all myeloma risk factors, over 60% correctly identified risk factors related to gender, age and race after the program (Figure 11). In addition, between 53 and 84% of participants answered questions about myeloma correctly after the in-depth education program, and participants “agreed” to “strongly agreed” after in-depth education programs that they learned information about myeloma (See Figures 12 and 13). Over 80% of participants in Topic-Specific Programs reported knowledge gains about different aspects of myeloma (Figure 14).

Figure 11 Knowledge of Risk Factors

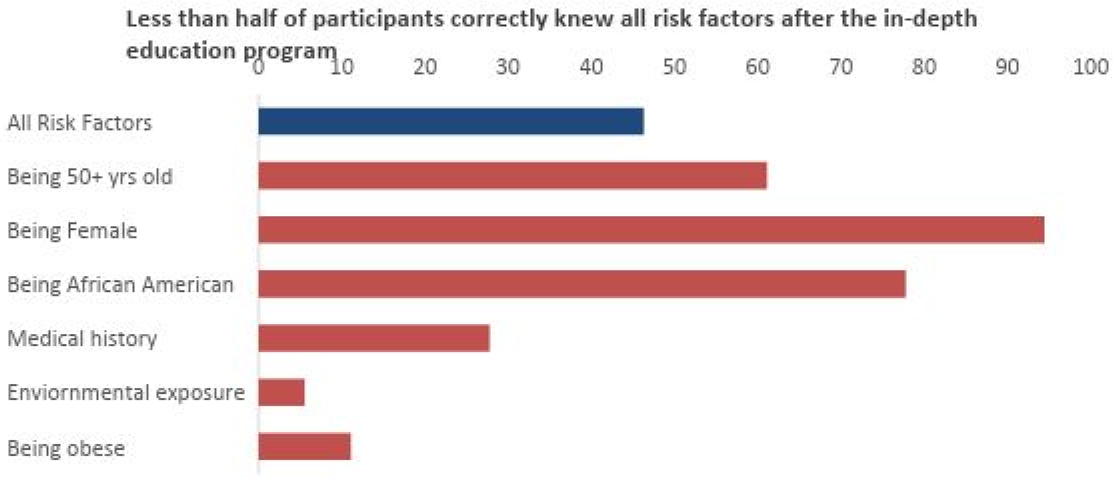


Figure 12 General Myeloma Knowledge

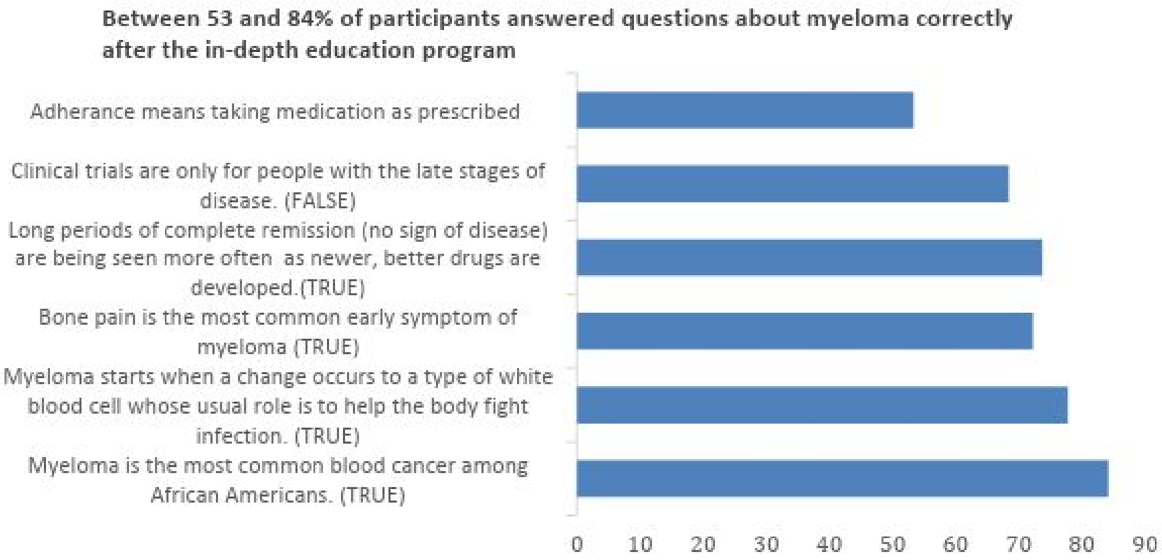


Figure 13 Reported Knowledge Gains- In-depth program

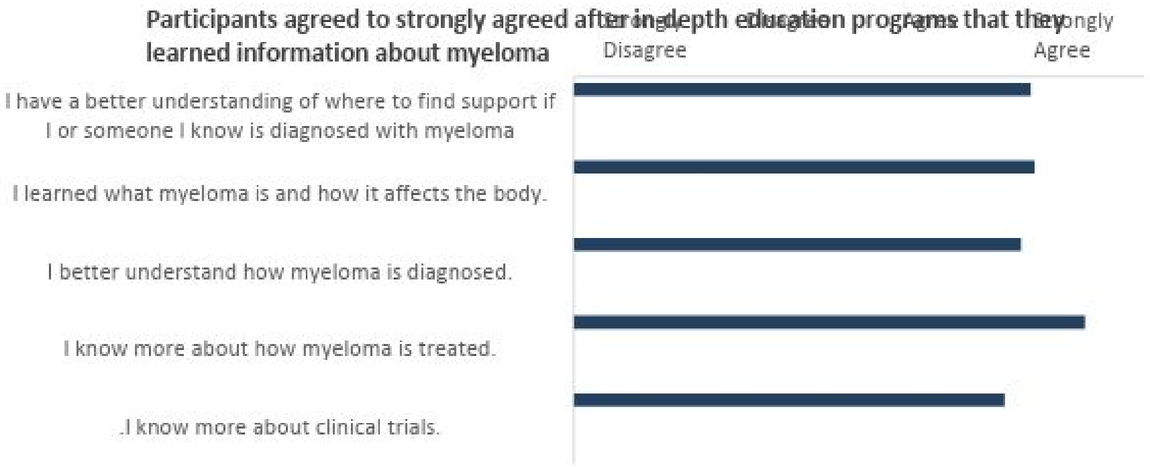
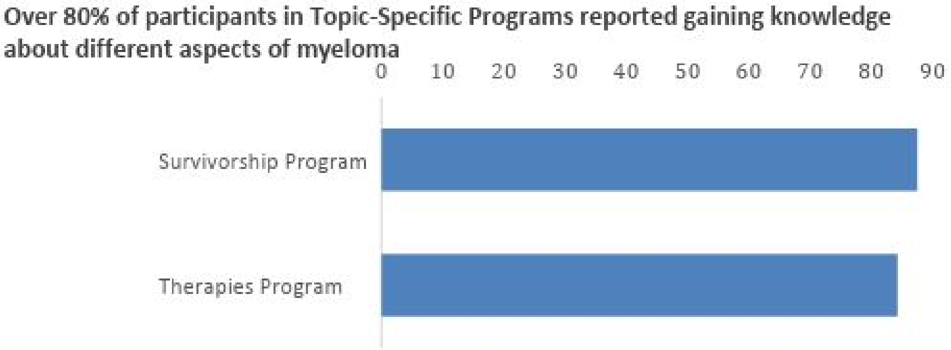


Figure 14 Knowledge Gains – Topic Specific Education Program



Increased awareness/knowledge – Interview results

All CSPs reported a significant increase in their own knowledge and awareness of myeloma and diagnosis, treatment and resources for persons with myeloma. In addition, ambassadors and CSPs were asked to describe any observations of increased knowledge and awareness among participants. All three ambassadors and some of the CSPs reported a significant increase in knowledge and awareness of myeloma and treatment and diagnosis of myeloma among participants, particularly during the education programs.

> *When the participants attend the education program – there are many ways that they can learn*
>
> *They went from 0 knowledge to 95% knowledge about resources.*
>
> *Opened the participants up to a wealth of knowledge.*

Participants' changes in their social support

Ambassadors and CSPs provided some important suggestions for improving social support among Black and African-American myeloma patients/caregivers in the community. These suggestions related to the following: 1) promoting and disseminating LLS resources; 2) connecting patients to health care providers, social workers, and other resources; and 3) providing support groups at local churches (Figure 15).

LLS assessed whether myeloma support groups for patients and caregivers were needed in the pilot cities with a particular focus on the need for any church-based support groups. Support group facilitators and oncology social workers provided information about local myeloma support groups and the need for addition groups through phone interviews and online surveys. In addition, a map of existing support groups in both cities was created. Results showed that, most recommended locations for new support groups fell within 5 miles of an existing support group suggesting a need to better promote and increase awareness of existing groups to patients and caregivers in the area as opposed to creating new support groups.

Figure 15 Suggestions for Improving Social Support

Promotion and Dissemination LLS resources

Disseminate brochures that include specific and local resources for myeloma patients

Utilize hospitals in some capacity to promote the Myeloma Link Project

Educate people about organizations like LLS that provide social support in a variety of forums

Alert the community that there is an abundance of free resources/conferences/meetings offered by LLS

Connect Patients to Resources

Connect myeloma patients and their families with social workers to aid in providing social support

Connect them to resources…Give them a direct connection

Support Groups

Form (small) social support groups at the actual churches, so the patients would be with people they already have a strong connection

Promote open support groups and LLS meetings more effectively

Participants' increase in disease management skills/behavior to help them navigate the

Ambassadors and CSPs provided open-ended suggestions for how to help myeloma patients increase their skills/ and behaviors to better navigate treatment and to more effectively cope with their disease. These suggestions focused on continued communication and an increase in patient education and empowerment so patients can reach out to health professionals and other patients for appropriate support (Figure 16).

Figure 16 Suggestions on how to increase patients' skills/behaviors

Communicate and Connect to Health Care Providers & Patients

Talking about the disease raises awareness and removes stigma ultimately encouraging new patients to seek help

Connect to patients who can share experiences

[Connect to] cancer centers house social workers who provide emotional support and teach coping skills

Education

Include diet and exercise in myeloma educational programming

Teach patients to bring someone with them to doctors' appointments and get ALL questions answered

Empowerment

Empower patients to make themselves available and become involved with LLS

Keep them involved and immersed in the LLS programming (webinars, telephone access, conferences)

V. Conclusions and Recommendations

This report contains the findings from an evaluation of the pilot Myeloma Link program implemented in Atlanta and D.C. The evaluation activities included surveys to evaluate the Myeloma Sundays sermons, Fellowship Hours, In-depth and Awareness Education Programs as well as in-depth interviews with project staff, ambassadors, community support participants (CSPs) and tracking of other activities and events. Overall, Myeloma Link staff and participants reported high satisfaction with the Myeloma Link activities, particularly the education programs. Several challenges were note with respect to delivering the Myeloma Sundays through churches, especially during worship hours. In general, participants of the Myeloma Sundays and Education Programs reported awareness and knowledge gains.

Some useful recommendations for improving the pilot program were provided by interviewees related to the following aspects of the program: 1) Broadening reach to patients by increasing presence of LLS in the community and connecting with other organizations beyond churches, 2) Re-examining the role of volunteers and ambassadors and creating tools for volunteers and organizations to deliver Myeloma Link activities on their own, 3) Expanding promotion of the program, and 4) Increasing the number of education programs delivered.

It is recommended that LLS review all individual suggestions and consider improvements in the following areas: 1) Expand the process of partnering with churches (e.g. create a LLS presence in the community before the program, offer programs outside of the worship time, partner with organizations of church leaders); 2) Maximize word of mouth marketing for Myeloma Link by identifying and connecting with key influencers in the target population, connecting with the community, and eliciting feedback from participants and community members throughout the program; 3) Expand the marketing campaign with traditional and social media activities; 4) Develop a consistent and streamlined tracking and data collection system; and 5) Connect with health care providers and organizations and implement more education programs to expand the reach of Myeloma Link to myeloma patients and caregivers.

Information and recommendations offered by the participants in this evaluation provide LLS with useful information on ways to expand the Myeloma Link program and reach Black and African American myeloma patients and caregivers so they are informed, supported and have the resources they need to manage and treat myeloma.