

Lifestyle and Self-Management by Those Who Live It: Patients Engaging Patients in a Chronic Disease Model

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ABSTRACT

Background: Patients pursuing organ transplantation have complex medical needs, undergo comprehensive evaluation for possible listing, and require extensive education. However, transplant patients and their supports frequently report the need for more lifestyle and self-management strategies for living with organ transplantation.

Objectives: First, to explore feasibility of a successful, patient-run transplant lifestyle educational group (Transplant Living Community), designed to complement medical care and integrated into the clinical setting; and second, to report the major themes of patients' and supports' qualitative and quantitative feedback regarding the group.

Methods: Informal programmatic review and patient satisfaction surveys.

Results: A total of 1862 patient satisfaction surveys were disseminated and 823 were returned (response rate, 44.2%). Patients and their supports reported positive feedback regarding the group, including appreciation that the volunteer was a transplant recipient and gratitude for the lifestyle information. Five areas were associated with the success of Transplant Living Community: 1) a "champion" dedicated to the program and its successful integration into a multidisciplinary team; 2) a health care environment receptive to integration of a patient-led group with ongoing community development; 3) a high level of visibility to physicians and staff, patients, and supports; 4) a clearly presented and manageable lifestyle plan ("Play Your ACES"^a [Attitude, Compliance, Exercise, and Support]), and 5) a strong volunteer structure with thoughtful training with the ultimate objective of volunteers taking ownership of the program.

Conclusion: It is feasible to integrate a sustainable patient-led lifestyle and self-management educational group into a busy tertiary care clinic for patients with complex chronic illnesses.

and mental health.²¹ Additionally, the positive effects of educational interventions are sustained longer with support involvement.²¹ Both transplant patients and their supports report the need for more comprehensive education and, in particular, lifestyle and long-term self-management, because this is frequently not addressed or not adequately addressed by hospital staff.^{5,22-25} However, there are gaps in available evidence on the education of support systems in the context of organ transplantation.

The provision of patient-centered care with efficient use of resources has become the quality standard in today's health care environment.^{26,27} Integration of the posttransplant patient into the plan of care provides an alternative way to meet a quality standard that has been successful with other patient populations.²⁸ However, strategies to address lifestyle and self-management in organ transplant patients have been limited to information gathering (eg, patient focus groups), nurse-led education groups, or other multidisciplinary team-protocol refinements.^{3,29-31} Although these are important first steps, their findings support the need for integration of transplant patients in the refinement of resources and education on successful lifestyle and self-management strategies.

The purpose of this study was 2-fold: 1) to explore the feasibility of a successful, patient-run transplant lifestyle educational group designed to complement medical care and integrated into the clinical setting, and 2) to report patients' and supports' qualitative and quantitative feedback regarding the group.

INTRODUCTION

Patients with end-stage organ disease referred for possible organ transplantation are a highly complex, multimorbidity population. Given the medical and psychosocial complexities, including potential patient impairments (eg, cognitive or physical disability) and provision of care through multidisciplinary teams, these patients require a great deal of education on the transplant process and ongoing support.¹ Nurses, social workers, physicians, and surgeons are the most frequent providers of education to end-stage organ disease patients who are pursuing transplant.²⁻⁴

Disease management programs are considered an important component of care for patients living with a transplanted organ^{5,6} and have been associated with positive outcomes such as improved patient satisfaction and adherence.^{7,8}

Patients with end-stage organ disease have increased risks for cognitive impairments secondary to their illnesses.⁹⁻¹⁷ Educational programs must take into account the patient's ability to process and recall educational information provided.¹⁸⁻²⁰ Involvement of family members in the care of patients with chronic diseases significantly increases patient physical

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Transplant Living Community: Program Success and Feasibility

The Henry Ford Health System Transplant Living Community (TLC) was established in 2008 via a collective patient initiative. TLC is a patient-to-patient organ transplant education program aimed at increasing patient and family awareness of necessary lifestyle changes throughout the transplant process. The framework for the program incorporates foundational principles of successful hospice, geriatric, pediatric, and cancer patient advocacy. The program is subject to institutional oversight and exists as an “ambassador” (volunteer) program to support patients, living donors, supports, and families throughout the transplant process. Transplant recipients are welcome to volunteer (beginning the service no sooner than 10 months after the transplant) and undergo an extensive training curriculum that covers empathic listening skills, appropriate medical referral to physicians, Health Insurance Portability and Accountability Act regulations, TLC platform materials, and continued mentoring. Training occurs during 2 full days (16 hours) followed by several weeks of supervised in-clinic training with established ambassadors. All ambassador volunteers are transplant recipients, representing heart, lung, kidney, pancreas, liver, multivisceral, and bone marrow transplants. However, ambassadors and patients are not matched based upon organ received. Ambassador volunteers provide interactive, onsite support within clinic and inpatient floors daily Monday through Friday. Since 2008, there have been more than 40 active ambassadors.

The primary goal of TLC is expressed to patients as “Play Your ACES!”^a (Attitude, Compliance, Exercise, and Support), which highlight important areas of self-management skills necessary for successful transplant, with an easy-to-understand, patient-centered approach. The elements of “Play Your ACES!”^a are not unitary constructs but represent an adaptive lifestyle approach while living with chronic illness. *Attitude* refers to more than positivity; it means having a “fighting attitude,” which is a more active coping strategy to manage the instability of living with chronic illness and embracing the new normal of living with an organ transplant. *Compliance*

focuses on the lifestyle elements of adhering to a complicated treatment regimen amid real-life circumstances, which could create obstacles or challenges to taking optimal care of oneself—for example, exploring and strategizing on environmental or social barriers that may hinder the patient’s ability to adhere. *Exercise* includes redefining exercise to make it attainable with small incremental increases in activity (eg, walking 25 steps today, 35 steps tomorrow) and using charting tools to track progress. This allows for small successes to be recognized and reinforces physical activity. Lastly, *sup-*

port is a multimember team for long-term support. TLC defines the duties of each person with a conceptualized approach. Some of the support roles include CEO or primary care manager, assistant CEO, drivers, medication manager, comedian, exercise buddy, spiritual caretaker, and other tangible support (eg, mowing the lawn, making meals, babysitting). All education and materials are presented in the patient voice (avoiding medical jargon) from a patient perspective and address only lifestyle components. All medical aspects of transplant are referred directly to medical staff and remain in the medical domain. TLC provides organizational tools and education to help patients navigate their medical care on a daily basis. TLC addresses caregivers as team members and provides a stylized support team approach involving the entire family in a positive, cooperative manner throughout the continuum of care.

What is truly unique about TLC, besides being entirely patient run, is its successful integration into routine clinical care. Within the waiting room of the main clinic there is an information table, staffed by an ambassador volunteer during normal clinic hours, dedicated to providing TLC educational and related materials. Medical personnel can also “refer” patients to TLC. When patients and supports return for the routine educational meeting (“family meeting”), required for listing for transplantation, TLC provides a component

of the education on self-management skills and posttransplant lifestyle changes. Within the TLC education, both patients and supports are addressed as a team unit where specific conceptualized home support team assignments are identified to include all family members, other supports, and extended support structures. For patients who undergo transplantation, a TLC ambassador visits the patient before discharge and provides him or her with a TLC Toolkit complementing prior pretransplant TLC education. The TLC Toolkit contains personal health recording

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tools with a tabbed notebook for Medications, Lab Tests, To Do Lists, Medical Records, and General Information. Other materials consist of support team contact and assigned duty outline, medical team contact card sleeve, calendar, medication charting tools, medication box, pill cutter, medication travel bag, thermometer, pedometer, emergency medication key fob, surgical masks, TLC button for social experiment, hand sanitizer, “Play Your ACES!”^a support materials, food safety guide, transplant lifestyle information, organ donation (Gift of Life) and registry information, donor contact guidelines, and tote bag. The TLC ambassador volunteer reviews educational resources within the toolkit in addition to answering or referring any questions of concern.

METHODS

Informal Program Evaluation

TLC has undergone continuous informal programmatic evaluation since its inception in 2008. First, as part of the kits provided to patients, there is a feedback form for suggestions to improve any resources or processes. Second, as part of a Patient Family Advisory Council, which involves physicians, staff representation from each hospital unit, and TLC ambassadors, all participating members provide feedback and recommendations. For the purposes of this article, the contributing authors identified and reviewed the elements of TLC that were thought to have a

high level of impact on the feasibility and sustainability of the group. The results of the programmatic evaluation are in the discussion section.

Patient and Support Feedback Evaluation

All data were collected with full institutional research and administrative approval. A patient and support satisfaction survey was developed for the purposes of this study to assess patient and support satisfaction with TLC-related education. The surveys were disseminated (via passive consent; the cover letter that explained completion of survey indicated consent) before the TLC component of the routine educational meeting for listing for transplant and were entirely anonymous to maximize response rates. Respondents

were invited to return surveys either directly to staff or in a locked box located within the clinic. Data collected in the survey included basic demographic characteristics (sex, race/ethnicity), organ needing transplant, and whether the respondent was the patient, primary caregiver, or other support person. Respondents were then asked to rate the TLC educational program on length, helpfulness, understandability, whether it met expectations for education, and confidence that the information provided would help them navigate the transplant process. They were assessed for recall of basic information presented in the TLC portion of the presentation (eg, “What does ACES stand for?” and asked to write in a response). Lastly, they were given the opportunity to provide

qualitative feedback on what they liked the best and least about the TLC portion of the informational session. The assessment is available online at: www.thepermanentejournal.org/files/15-207Appx1.pdf.

Analyses

Participant’s responses were compared between groups by χ^2 test for categorical variables and Kruskal-Wallis H test for continuous variables. For qualitative responses, 3 of the authors (ER, CW, and MT) individually classified the responses on the basis of content and assigned numerical labels to the comments (dummy coding) corresponding to thematic content. Following dummy coding, all numerics were sent to another author (MJ), who reviewed the data and selected scoring on the basis of a majority of responses. For example, if 2 coders reported a statement was a “2” but a third coder reported the statement was a “3,” the statement was coded as a “2.” Frequencies of all codes were then analyzed for frequency of content.

RESULTS

Patient Evaluation and Feedback

Surveys were collected from January through November 2013. Of the 1862 surveys disseminated, 823 surveys were returned (response rate, 44.2%). The mean (standard deviation) age of patients was 54.1 (11.5) years, of primary supports was 51.97 (14.24) years, and of other supports was 46.48 (16.22) years. Additional demographic and respondent characteristics are presented in Table 1.

Table 2 provides the frequency of correct responses on defining compliance and ACES. There was no significant difference between respondent groups in defining ACES but there was a significant difference in defining compliance, with patients having the highest frequency of incorrect responses.

A Kruskal-Wallis H test was run to compare patients, primary supports, and other supports on satisfaction with the TLC presentation. There was a statistically significant difference on how confident respondents reported feeling after meeting with the TLC ambassador ($p = 0.002$), with secondary supports reporting the highest confidence followed by primary support and lastly patients. There

Table 1. Characteristics of 823 respondents in study of Transplant Living Community^a

Characteristic	Patients (n = 217)	Primary caregivers (n = 255)	Other supports (n = 351)
Sex			
Men	130 (59.9)	56 (22.0)	140 (39.9)
Women	72 (33.2)	188 (73.7)	201 (57.3)
Hispanic/Latino			
Yes	9 (4.1)	10 (3.9)	11 (3.1)
No	176 (81.1)	209 (82.0)	305 (86.9)
Prefer not to respond	5 (2.3)	5 (2.0)	2 (0.6)
Middle Eastern			
Yes	5 (2.3)	4 (1.6)	2 (0.6)
No	172 (79.3)	209 (82.0)	310 (88.3)
Prefer not to respond	4 (1.8)	5 (2.0)	3 (0.9)
Race			
American Indian or Alaskan Native	2 (0.9)	—	5 (1.4)
Black or African American	70 (32.3)	57 (22.4)	64 (18.2)
Other Pacific Islander	1 (0.5)	1 (0.4)	1 (0.3)
Asian	2 (0.9)	4 (1.6)	1 (0.3)
White	127 (58.5)	174 (68.2)	256 (72.9)
Other	5 (2.3)	2 (0.8)	6 (1.7)
Prefer not to respond	1 (0.5)	2 (0.8)	8 (2.3)
Multi-ethnic	5 (2.3)	8 (3.1)	4 (1.1)
Organ			
Liver	112 (51.6)	171 (67.1)	285 (81.2)
Heart	—	1 (0.4)	—
Kidney	94 (43.3)	66 (25.9)	52 (14.8)
Pancreas	2 (0.9)	1 (0.4)	—
Lung	1 (0.5)	1 (0.4)	—
Liver/kidney	3 (1.4)	3 (1.2)	4 (1.1)
Kidney/pancreas	2 (0.9)	2 (0.8)	1 (0.3)
Other	2 (0.9)	1 (0.4)	—

^a Data are presented as number (% of category) unless otherwise noted. Within categories, columns do not consistently add up to the total because of missing data.

— = no affirmative responses.

were no significant differences between respondent groups on expectations being met ($p = 0.699$), information being easy to follow and understand ($p = 0.241$), whether the information presented will help navigate the transplant process ($p = 0.174$), or length of the session ($p = 0.364$); see Table 3.

For qualitative data, as scored above, 633 of the respondents (76.9%) wrote in a reply for what they liked the most

about the TLC portion of the educational session. Several respondents received more than 1 code if the content of their response addressed more than 1 thematic area. Aspects of the program that generated the most frequent positive responses are included in Table 4 (percentages are out of those who provided qualitative feedback). When asked what they liked the least about the TLC portion of the educational session, 199 of the respondents

(24.2%) responded. Themes identified (in order of frequency of occurrence) are also reported in Table 4.

DISCUSSION

TLC is a unique, sustainable, patient-led lifestyle and self-management educational program providing a valuable resource for organ transplantation patients and their caregivers. Prior research has shown that transplant patients report a lack of caregiver education and acknowledge the need for distributed educational opportunities during the course of transplant.⁵ The Institute of Medicine's 2000 report³² called for engaging and empowering patients in health care. Since this seminal report, patients are becoming more proactive consumers, actively participating in their care. However, as others have outlined, practical guidance on how to engage patients has been limited.³³⁻³⁵ For patient engagement to be successful, patient education must address lifestyle skills. This education will need to come from the patient's perspective, complement medical care, and involve patients, caregivers, and extended social support members. An example of this approach, in which lifestyle methods are applicable across many chronic disease populations, is the TLC. Patients and supports reported high levels of satisfaction with the lifestyle and self-management skills presented by the TLC. Respondents also frequently indicated appreciation for having an actual transplant recipient providing the information as they felt this made the information more accessible and gave them hope for the future. When asked about possible improvements, most of the responses indicated nothing, or provided suggestions that were logistical or unrelated to TLC (eg, protocol requirements for transplant).

An interesting finding was that patients were significantly less likely to correctly identify the components of compliance than were primary or other supports. As outlined in the introduction, end-stage organ disease has a well-documented association with the development of cognitive impairments.⁹⁻¹⁷ This underlines the importance of providing relatable lifestyle and self-management education not only to the patient but also to primary and secondary supports throughout the care continuum.

Table 2. Responses to survey about Attitude, Compliance, Exercise, and Support in study of Transplant Living Community^a

Survey responses	Patients (n = 217)	Primary caregivers (n = 255)	Other supports (n = 351)	p value
What does compliance mean?				
Responded correctly	171 (78.8)	219 (85.9)	308 (87.8)	0.008
Responded incorrectly	39 (18.0)	32 (12.5)	32 (9.1)	
Did not respond	7 (3.2)	4 (1.6)	11 (3.1)	
Attitude ^b				
Answered correctly	173 (79.7)	188 (73.7)	266 (75.8)	0.462
Answered incorrectly	3 (1.4)	9 (3.5)	11 (3.1)	
Did not respond	41 (18.9)	58 (22.7)	74 (21.1)	
Compliance ^b				
Answered correctly	171 (78.8)	191 (74.9)	271 (77.2)	0.820
Answered incorrectly	4 (1.8)	6 (2.4)	10 (2.8)	
Did not respond	42 (19.4)	58 (22.7)	70 (19.9)	
Exercise ^b				
Answered correctly	172 (79.3)	189 (74.1)	272 (77.5)	0.500
Answered incorrectly	1 (0.5)	5 (0.2)	4 (1.1)	
Did not respond	44 (20.3)	61 (23.9)	75 (21.4)	
Support ^b				
Answered correctly	169 (77.9)	183 (71.8)	256 (72.9)	0.163
Answered incorrectly	3 (1.4)	4 (1.6)	13 (3.7)	
Did not respond	45 (20.7)	68 (26.7)	82 (24.2)	

^a Data are presented as number (% of category). Percentages may not total 100 because of rounding.

^b Responses to the questions: What does ACES stand for?

Table 3. Respondent satisfaction with Transplant Living Community^a

Respondent satisfaction metrics	Patients (n = 217)	Primary support (n = 255)	Other supports (n = 351)
Adequate or not enough time in the TLC information session	201 (92.6)	235 (92.2)	332 (94.6)
The information presented was helpful or very helpful in managing the transplant process	204 (94.0)	240 (94.1)	323 (92.0)
The information presented was understandable or very understandable and easy to follow	211 (97.2)	243 (95.3)	335 (95.4%)
The TLC program met or exceeded expectations	203 (93.5)	237 (92.9)	322 (91.7)
Respondents were mostly or completely confident they could navigate the transplant process with the information provided by the TLC ambassador	191 (88.0)	211 (82.7)	284 (80.9)

^a Data represent affirmative responses. Data are presented as number (% of category).

TLC = Transplant Living Community.

Also interesting was that secondary supports reported the greatest confidence in being able to manage the transplant process following the TLC education class. For supports other than the patient's primary support, the TLC lifestyle and self-management education is often their first exposure to the seriousness and extensive nature of care for organ transplants. "Other supports" often come in knowing only that their relative or friend needs a transplant and may have had minimal tangible support requirements placed on them. The potential of secondary supports to be considered as integral support team members to assist the primary support role has not been explored and could be considered for further research to determine the accuracy of this interpretation.

There are a number of factors unique to the TLC and considered integral to its sustainability that would be useful in integrating a similar program. First, a "champion" or at least one person should be dedicated to the program and its successful integration into a multidisciplinary team.

Table 4. Frequency of qualitative (themes) responses to "liked most" or "liked least" about Transplant Living Community^a

Theme for "liked most"	
The volunteer/that the volunteer was a transplant recipient	359 (56.7)
Information provided	195 (30.8)
Overall positive experience with the program	69 (10.9)
Quality of the presentation	66 (10.4)
Have a reference for lifestyle-related questions	21 (3.3)
Theme for "liked least"	
Disliked nothing	136 (68.7)
Aspects other than the TLC presentation (eg, interruptions)	23 (11.5)
Inadequate time with TLC	12 (6.0)
Desired more information	10 (5.0)
Disliked the group format (would have preferred individual)	9 (3.9)
Disliked requirements or compliance factors related to transplant	8 (4.0)
Disliked the individual presenting	5 (2.5)

^a Data are presented as number (% of those who provided qualitative feedback for that theme). TLC = Transplant Living Community.

Transplant recipients have recognized the value of patient-to-patient interaction.²³ Secondly, a health care environment must be receptive to integration of a patient-led group with ongoing community development. Internally, a representative of TLC attends the selection committee to advocate for patients. TLC ambassadors have been instrumental within the Patient Family Advisory Council, driving the patient and family needs agenda with staff in a structured fashion. Medical staff trust has been developed and maintained through continual dialogue, the provision of a consistent curriculum, field mentoring of ambassadors, standardization of lifestyle resources and related tools, and routine practice of referring medical questions back to medical staff. Anecdotally, TLC involvement has fostered positive outcomes that reinforce ongoing trust from medical staff. At our center, there are several examples of patients who were determined not to be transplant candidates but, through interactions with TLC and its tenants, were able to meet eligibility for listing for organ transplantation. Third, the program must be accessible and visible to patients, supports, and staff. TLC has a centralized presence on the clinic floor via an educational table full of resources manned by a TLC ambassador in addition to TLC dedicated e-mail and voicemail access. Fourth, a clearly presented and manageable lifestyle plan ("Play Your ACES"^a) is needed. Related information and resources are presented in a clear and useful format accessible to most patients. Resources (eg, informational packet, brochures) are routinely evaluated and updated or improved to maximize utility and accuracy. Lastly, a strong volunteer structure with thoughtful training/orientation contains the ultimate objective of volunteers taking ownership of the program. Transplant recipients are invited to become ambassador volunteers only after a minimum of ten months after the transplant to ensure adequate physical and psychological recovery, wellness, and stability.

This study has several limitations. First, the assessment of the satisfaction of patients and supports was at a single time point and therefore the level of satisfaction and information retained may be

different following repeated exposure (as that is the TLC model) or the overall experience with the program. Second, there is the potential for response bias. Patients and their supports were asked to complete the survey after an approximately three-hour educational session, which owing to patient fatigue or other factors may have reduced our response size. Lastly, given that TLC is a well-established community of ambassadors integrated into the clinic with patients routinely exposed to the TLC group, whether TLC has a significant impact on patient outcomes at this time could not be determined. To ascertain whether this is the case, randomized controlled trials would need to be performed. Future research should attempt to parse the effects of similar interventions on patient-related outcomes. However, one of the true strengths of this group is its visibility and accessibility, suggesting a multisite study with similar patient sociodemographic characteristics would be an optimal strategy.

CONCLUSION

It is entirely feasible and sustainable to integrate a patient-led lifestyle and self-management educational group into a busy tertiary care clinic for patients with complex chronic illnesses. This requires a receptive and supportive health care environment, a coordinated and cohesive patient volunteer structure, and continued improvement. Furthermore, overwhelmingly positive feedback from patients and their supports regarding such a group suggest that these groups could provide substantial benefits in the care of complex illnesses. ❖

^a "Play Your ACES" is service marked. For those interested in more information, please contact Elizabeth Rubinstein at erubins1@hfnhs.org.

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To Interact

It is our duty to remember at all times and anew that medicine is not only a science, but also the art of letting our own individuality interact with the individuality of the patient.

— Albert Schweitzer, 1875-1965, French-German theologian, organist, philosopher, and physician