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Adolescent and Young Adult Palliative Care at the UFHealth Streetlight Program: Impacts on Pre-medical and Pre-healthcare Professionals

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Abstract

Clinical and research literature in medical education indicates a dearth of opportunities to adequately and competently prepare young pre-medical and pre-healthcare professionals to attend to the needs of dying patients, especially youths and their families. This study aimed to explore outcomes of an innovative palliative care program on 142 past and present pre-medical and pre-healthcare student volunteers. Results of the mixed-methods study indicate that the *Streetlight* program significantly impacted these student volunteers' sense of empathy, compassion, and comfort in attending to dying adolescents and young adults. Qualitative themes included the following: leadership vision, investment among members, member characteristics, relationship with self, learning about others, learning about professions, learning about the healthcare system, spirituality, appreciation for life, and emotional connections. Given the apparent lessons reported by the past and present student members who participated in the study, the *Streetlight* program may be a viable model for introducing pre-medical and pre-healthcare students to compassionate palliative care.

Keywords: Adolescent and young adult palliative care, Pre-medical and Pre-healthcare education, Compassionate medicine, Program evaluation

Article

One of the most challenging situations for young healthcare professionals—and one of the richest experiences—is serving patients who are dying. Deaths that occur early in a clinician's education can have strong emotional consequences that clinicians might be improperly equipped to deal with (Jackson et al., 2005). Within medical education there is a growing realization that students and young clinicians need more real-life experiences in clinical and community settings (Dornan, Littlewood, Margolis, Scherpbier, Spender, & Ypinazar, 2006) and are inadequately prepared, in particular, to fully address the issues associated with a dying patient (Patel, 1999), especially youths and their families (Whitcomb, 2002). Patients, caregivers, and various health professionals have concerns about the knowledge and quality of palliative care that is being provided (Abma & Widdershoven, 2005). The use of role-play experiences to teach palliative care to undergraduates and graduates has long been shown to benefit student clinical engagement (e.g., see Charlton, 1993) and "there is almost universal support for the inclusion of teaching in this area in all undergraduate curricula" (Lloyd-Williams & MacLeod, 2004, p.683). Therefore, there is a critical need for medical

education to provide formal end-of-life care training for medical professionals to take into account the psychosocial aspect of care (Larson & Larson, 2002). Researchers have indicated the necessity for future doctors to have training in the holistic "art of medicine" rather than the science of preventing death and prolonging life (Patel, 1999, p. 382). A gap in the literature exists related to qualitative and mixed-methods reporting on palliative care (Farquhar et al., 2013). Specifically, few studies have examined the impact of palliative care programs on pre-medical and pre-healthcare professionals' capacity to attend to the needs of dying adolescent and young adult patients.

With the understanding that adolescent and young adult patients and their grief stricken families are often overwhelmed by their life circumstances, other members of society must rise up and advocate for this population (Pritchard, Cuvelier, Harlos, & Barr, 2011). An intentional effort is needed to transform the attitudes and beliefs of clinicians who serve adolescents and young adults with life-threatening conditions (Rushton, 2004). Physicians admit that technology-based, fast-paced hospital environments can often distract healthcare professionals from truly connecting with their patients on an interpersonal level (Mendler, 2005). Internal barriers, such as strong emotions, poor communication skills, or inadequate understanding of palliative care can manifest as distress and ethical dilemmas (Rushton, 2004). Medical students and residents have little training in communication with dying patients and their families (Ury, Berkman, Weber, Pignotti, & Leipzig, 2003). In contrast to psychological fields, medical professionals are not trained to recognize, respond to, and communicate about the powerful emotional reactions that can be a consequence of patients' life-threatening illnesses (Jackson et al., 2005).

Researchers have pointed out that the World Health Organization (WHO) recognizes the significance of tending to the mind, body, and spirit of children who need palliative care, as well as their caregiving families (Pritchard et al., 2011). Holistic attention seems to enhance patients' physical, emotional, and spiritual well being (Silver, 1981). Although the American Academy of Pediatrics recommends palliative care should be offered at the inception of a diagnosis and for the duration of the treatment (Schmidt, 2011), adolescents, young adults, and their families often have limited access to hospice services that accommodate their unique situation (Rushton, 2004). Physicians have acknowledged the potential inadequacy of pediatric or adult palliative care services to serve adolescents and young adults with their complex and unique medical and psychosocial needs (Pritchard et al., 2011; Rushton, 2004). Because peer support at this phase of identity development is crucial, grief about changes in friendships due to their illness is an important consideration (Pritchard et al., 2011). The *Streetlight* program is structured to provide adolescents and young adults with meaningful and genuine peer interactions to help bring connection and support to this vulnerable population at a challenging time in their lives.

The *Streetlight* Program

Streetlight is a psychosocial adolescent and young adult palliative care program that aims to address the needs of critically and/or terminally ill youths ages 13 to 25 and to provide pre-medical and pre-healthcare professional students with a critical formative experience. Selected undergraduate students who are majoring in pre-medical and pre-healthcare professions initiate long-term, supportive relationships with hospitalized adolescents and young adults and, in so doing, learn empathy and compassion through real-time, transformative experiences prior to medical school or other healthcare professional education. These pre-professional students learn to care in the context of their future work, and the adolescents and young adults gain meaningful peer relationships, which they crave but rarely find.

According to Rebecca Brown, *Streetlight's* founder, the program's name was chosen because *Streetlight* implies that spiritual light is accessible not only from sacred scriptures, but also can be found "on the street," where adolescents and young adults converge to visit (R. Brown, personal communication, April 25, 2012). At the time of this research, *Streetlight* had served more than 1,200 adolescents and young adults, half of whom were designated palliative patients and many of whom have died. *Streetlight* student volunteers (referred to as student members in the program) frequently draw upon the *Streetlight* motto, "We get to carry each other" from the chorus of U2's song "One" (1991), to convey their experiences, describing the opportunity to carry patients as a blessing and a privilege. There have been no less than 12 patient deaths "carried" by *Streetlight* team members yearly (R. Brown, personal communication, April 25, 2012).

In this mixed-methods study, we qualitatively explored the impact of this unique program on its student members (see emergent themes presented under Qualitative Research) and quantitatively tested the following hypotheses:

Hypothesis 1: As a result of their *Streetlight* experience, student members would be better able to understand, empathize, and cope with issues related to a chronic and/or terminal illness, death, dying, and suffering at the end of life. *Streetlight* would help them to improve their communication skills, to understand and have a greater respect for people from different backgrounds, to appreciate life more, and to develop service as a stronger core value in their lives.

Hypothesis 2: Student members who had volunteered longer with *Streetlight* and reported that service became a stronger core value in their lives (compared to before their *Streetlight* experience) would report the greatest gains in the following: understanding, empathy, coping with end-of-life issues, communication skills, understanding and respecting people from different backgrounds, and appreciation of life. They would also experience the greatest personal, spiritual, and professional transformation through their volunteering with *Streetlight.* It was expected that students' longer exposure to the experiences of chronic and terminally ill adolescents and young adults and their increased willingness to serve this population made them more amenable to the lessons offered through *Streetlight.*

Methods

Research Team

The research team was comprised of three faculty members and four doctoral students representing the disciplines of counselor education, higher education, sociology, and neuroscience. The first and second author conducted all individual and focus group interviews. Audio recordings were professionally transcribed, and the four doctoral students conducted the thematic analyses of data under the first author's supervision. The survey research and analyses were conducted by the first and sixth authors.

Participants

Purposeful sampling was used to recruit all participants. According to the *Streetlight* director, since its founding in 2005, current and former members number around 200 (N=200; R. Brown, personal communication, April 25, 2012). Participants were undergraduate pre-medical, pre-healthcare professions, or first, second, and third-year medical students who had served or were serving as *Streetlight* student members. A mixed-methods research design was used to evaluate the impact of participating in the *Streetlight* program as a student member. The qualitative study was conducted first (Fall 2012), followed by the quantitative survey (Spring 2013). All current and former *Streetlight* members received invitations via email and a dedicated, closed, social media page to participate in this mixed-methods study. The invitation was distributed by the *Streetlight* director on behalf of the research team.

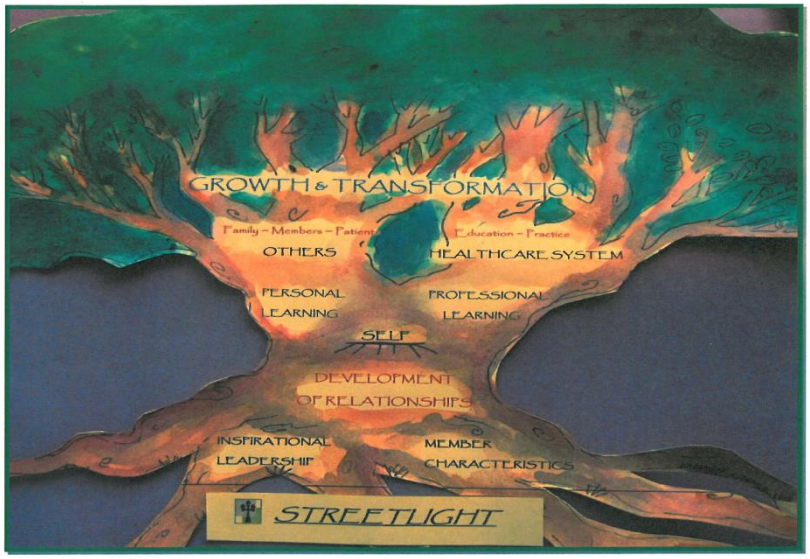
Qualitative Research

Current and former *Streetlight* members who were interested in participating in the qualitative interviews (n = 50) contacted the research team leader (first author), and interviews were coordinated, scheduled, and held by the first and/or second author or both. A total of 13 individual and seven semi-structured focus group interviews (a 25% response rate for the qualitative research) were conducted. The focus group interviews ranged from three to seven participants. Semi-structured interview questions were co-developed by the program director and the research team. The open-ended questions aimed to capture the members' perceived impact of the program on their professional and personal development and their perceptions of palliative care delivery. Institutional approval was obtained and consent forms were signed before each interview. The individual and focus group interviews ranged from 45 to 90 minutes.

Qualitative analyses and results.

Working in dyads, the four doctoral student authors coded the 20 individual interview and focus group transcripts. Each dyad was assigned 10 interviews which were independently coded by a dyad partner. Using a modified grounded theory approach (Glaser & Strauss, 1967), each pair of coders created preliminary line-by-line codes and memo jottings. The preliminary line-by-line codes and memo jottings (Liamputtong & Ezzy, 2005, as cited in Saldaña, 2009) were compared and contrasted by each dyad until agreement was reached on the initial coding. At team meetings of the two dyads and the first author, dozens of initial open codes (Shank, 2002) were organized and consolidated into emergent themes. Iterative analyses and discussion resulted in grouping the themes into foundational, structural, and overarching categories.

Inspired by the frequent reference to metaphors by the participants, the team conceptualized these categories as representing the parts of a tree (see Figure 1).



In this conceptualization, a tree has grown from the initial seed planted by the program director and founder. Her inspirational leadership along with the student members' individual and common group characteristics forms the foundation or roots of the tree. The roots nourish a trunk that provides the structure in which student members' selves develop. The trunk then branches out into a full, overarching canopy of growth and transformation. Within this metaphorical construct, themes emerged and were grouped into three categories: (a) the foundational roots capture leadership vision, investment among members, and member

characteristics; (b) the structural trunk develops through learning experiences about self, others, professions, and the healthcare system; and (c) the overarching canopy embodies spirituality, appreciation for life, and emotional connections experienced by student members. The following section describes each salient theme and provides verbatim examples from the transcribed data to illustrate each theme.

The roots: Inspirational leadership.

Leadership vision. Brown's vision and leadership has rippled throughout the *Streetlight* program. Many of the participants attributed interactions with Brown as positively affecting their program experience, career aspirations, or personal lives. One of the members explained it as follows:

> We've had such a leader who has such vision and whose heart is in such the right place… I feel like we all try to be like her, and we all try to emulate that same amount of love that she has for all the patients and all the volunteers.

The care and concern Brown demonstrated for patients and members inspired participants not only to invest the same level of care in patients and each other, but also to develop an overall sense of community. The program's daily communication structure helped to cement this sense of care:

> You get there and you're briefed every day, sort of like a 'rounds' on status of all the patients. That helps you both focus your mindset and stay up-to-date with everybody. That was exceptional…. There's a lot of intangible elements to it that [the director] specifically brought.

Incoming members were mentored by experienced members. Focused meetings at the beginning of shifts, social functions with patients, and outside social activities for members hosted by Brown fostered cohesion. For example, one participant described an experience where the "the whole ambiance of the campfire, her dog running around, making apple cider" created "a real bonding experience." Along with Brown's inspirational leadership, the other two foundational themes that were identified from participants' statements entailed the members' investment in the program and their personal characteristics.

Investment among members. Participants reported an investment in the program that mirrored Brown's passion for *Streetlight.* The amount of time participants spent volunteering regularly exceeded the required three hours per week. Though initially expecting to commit only a few hours per week, many participants reported returning to the hospital multiple times each week after forming deep connections with patients and other members. As volunteers, the participants expected that they would be the ones giving to the patients. However, one participant captured the feelings expressed by many who admitted that "it wasn't about what can I do for these patients… I got so much more out of that program. I know I put a lot in, but I think I got so much more out."

The bonding that occurred between patients and their student members fueled the desire to spend more time with each other as one member illustrated here: "I stayed way past my shift…. Technically, I should have left around like 8:30, and I was in his room till like 12 o'clock at night talking to his mom." Another member added that a sense of family connection sometimes developed as a result:
Yeah, they lose their friends, they are alone…. they have only their mom or dad or they have no support at all, and we kind of step in as their family, because I mean, we consider ourselves like family, so we support them like a family.

Some participants explained their choice to spend more time with patients by using the following metaphor:

> We're helping them build their sandcastle and …I know his sandcastle is going to get washed away, and he's going to be taken in by the wave. We feel the wave coming and we felt it coming for a very long time, but … we're having fun on the beach right now.

Member characteristics. The participants also highlighted personal characteristics which they perceived as making *Streetlight* an impactful program for all involved. In particular, members described the following characteristics: "natural gifts for being present, being mindful, being compassionately attuned to the needs of the patient" were viewed as "the special type of person" who volunteered for *Streetlight*. This was in contrast to other pre-medical and pre-healthcare students who as one member described were interested in "resume building" or who were "your typical pre-medical students that were cut-throat trying to, you know, do anything they can to make an A." Another participant added:
Everyone had these exquisite personalities…You want to be there for a patient's surgery or you want to be there for an end of chemo party… people that are just doing this for resume building … I do not recommend this program to them at all.

Inevitably, whether or not the members were a good match for this type of program, one participant acknowledged the common sentiment that "*Streetlight* is just one of those things, it doesn't matter who you are, it's going to affect you somehow, it will change you, make you a more compassionate person, someone who really cares."

The trunk: Relationship development.

Relationship with self. Just as the roots laid the foundation, the trunk provides structure for the development of a variety of relationships. The words of one participant were echoed by many others when she shared that "the relationship aspect is what really drew me—what kept me in *Streetlight* for the past four years." For many participants, these relationships were fostered by the participants' own personal learning about themselves. Not surprisingly, increased self-awareness and self-knowledge revolved around explorations of the meaning of life and death. These lessons impacted the student members deeply, realizing that "I only have this one life; I don't get a do-over; I'm going to do the best I can now and enjoy it." Student members acknowledged their experiences in *Streetlight* changed how they behaved in relationships with themselves and others as well as their way of being in the world.

For example, one participant described living life to the fullest and being present:

> If I'm with a patient, I want to be focused; I want to be there; I want to be in the room with them since neither of us are really going to get anything out of it if I'm not really there.

The hope and determination of the patients inspired another participant to state the following:

> One big lesson that I learned was never give up. Because I'm sure we've all seen patients who come in remission and they still keep fighting…Even though it looks like it's not going to happen or it looks like you're pretty much not going to live, [patients] still do their chemo or they still do their radiation, whatever they have to do in order for them to get a fighting chance.

Participants expressed feeling humbled and vulnerable as a result of forming genuine connections "with many sick kids who will pass away." By "establishing this connection, this bond with them at probably the most vulnerable time in their lives," one participant reflected "it's an honor to experience that dash in between birth and death." Instead of succumbing to grief during this period, another participant suggested that "death is not really something that always needs to be grieved over. Death can be a celebration, a celebration of some life."

Learning about others. The participants' evolving perspectives of themselves informed their relationships with patients, their families, and other *Streetlight* student members. Since "patients are often disconnected from their social circles, they need a nonjudgmental friend" who, according to one participant, will "listen to their stories, listen to their pain, listen to their joys." Through listening

and sharing, another participant discovered "how cultivating friendships and companionships can make a person grow exponentially." Another participant added "to learn their story on a deep level and to learn to be nonjudgmental and to be open-minded and understanding and accepting … regardless of their situation is another lesson of participating in this program."

Participants developed a greater understanding of the struggles that families go through which enabled them to develop relationships with family members. Describing single parents, one participant said they "can't just quit their jobs and drop everything since they still have other children to support. Participants said they were pleased to substitute for these parents and make up for the time they could not be there. Going "beyond the hospital borders," some participants reported that they "became a member of the family" by visiting patients in their homes, exchanging Christmas gifts, and attending a patient's graduation.

Participants were mindful that they depended on *Streetlight* leadership as well as each other for support and encouragement. One participant was confident that "I could contact any *Streetlight* member and they'd have my back" especially "if I'm stressed or if I'm sick, I can guarantee that *Streetlight* members will be there." When referring to the *Streetlight* motto: "We get to carry each other" members pointed out that, "you're not just carrying the patients; you are carrying your group." Members frequently drew upon the *Streetlight* motto to convey their experiences by describing the opportunity to carry patients as a blessing and a privilege.

Learning about professions. As participants broadened and deepened their relationships with self and others, they discovered new insights about their career callings. Many participants were interested in the medical field even before they became student members of *Streetlight.* However, numerous participants recognized that "there's no way to know what's going on in a hospital, what's going on with patients unless you have patient contact." The members' experiences in the *Streetlight* program both clarified and solidified their career choices and plans as explained by one participant: "I wasn't actually going to be a doctor, that wasn't my initial goal… But once I started volunteering, I think it sort of chose me." The following quote also exemplifies this sentiment:

> This program opened my eyes and heart to the reality of working with patients and the purpose that correlates with sitting with someone in their pain. I trust that anyone who works with *Streetlight* will experience profound shaping and stretching that will prepare them for a career in the helping professions.

Learning about the healthcare system. Participating in the *Streetlight* program exposed the participants to many aspects of the healthcare system. One participant emphasized the importance of healthcare providers taking "the time just to connect with a patient and look at them beyond what their disease diagnosis is." Most importantly, *Streetlight* helped a participant "take a step back when I'm seeing these patients and to try to see it from their perspective" since "a lot of these patients have other issues outside that may be affecting their healing and their recovery process." Participants suggested that more emphasis should be placed on addressing the psychosocial needs of patients in addition to their medical care. With a new appreciation for the experiences of patients, one participant was hopeful that someday she would "take off the white coat, and just sit down and talk" to her patients.

The canopy: Growth and transformation.

Participants credited their participation in the *Streetlight* program with significant personal growth. The overarching canopy represents the relevance of spirituality, an appreciation of the value of life, and the importance of emotional connections. These were predominant themes in the participants' discussions of the impact of *Streetlight* on their personal development. While each participant discussed these themes with varying intensity, they all agreed that *Streetlight* changed their lives.

***Spirituality*.** Trying to make sense out of why the 16-year-old who died was never able to graduate college or get married, why there is an innocent 15-year-old on her death bed, or why a young person is dying at all, elicited questions and raised issues about spirituality for the participants. Some participants reported that they relied on their faith to guide them. However, one participant observed that people "seemed to be more spiritual as opposed to more, you know Christian, Jewish, or Muslim." Seemingly, religious affiliations were irrelevant when searching for answers to existential questions. As one participant pointed out, "I don't know who you're praying to; maybe I'm praying to someone different; maybe we're not praying to anyone at all…. [it's] not a religious or cultural type of thing; it's kind of universal."

Appreciation for life. With an appreciation that life is incredibly precious and fragile, one participant advised that since "you don't know how much time you have…love the people around you." Conscious that "some things happen that are just beyond your control," one participant reminded herself to "say what you need to say when you're there with somebody. Spend time with them while you can, so don't take that time for granted."

Emotional connections. A significant number of participants described going into patients' rooms as "nerve-wracking" and made them feel "awkward," "timid," "scared," or with a "flutter in my chest." While one participant initially worried whether "I'm going to be able to connect with them at all," another participant learned to emotionally connect by "leaving it at the door… your ego. They can sense that right away." Entering the patients' rooms and eventually their lives enabled a participant to begin to understand that "illness is a very isolating experience; we tend to cordon off all the sick people, and so your average person walking around doesn't really have any idea what this does to folks." While listening to patients was noted as a crucial ingredient for emotional connection, one participant began "allowing silence when it needed to be, and allowing thick tension of uncomfortableness to be." When describing the transformation they experienced through emotional connection, participants used words such as "inspiring," "humbled," "more and more confident," and "open."

Some participants described the *Streetlight* program as being filled with courageous firefighters who enter a burning building with people who can be severely wounded and may not survive. Using this metaphor, one participant explained "our patients are like the burning building and everyone else is running out of their lives and we're running in." Lessons learned from the *Streetlight* experience were captured by one participant who advised not to "close yourself off from the people you're going to meet because you're worried about losing them."

Quantitative Research

To complement the qualitative findings, the research team developed a survey to quantitatively analyze the impact of *Streetlight* on its members. The aim was to explore the student

members' knowledge and understanding of palliative care, the program's impact on aspects of their comfort level facing patients' death and dying experiences, and how these experiences shaped the members' career expectations and paths. A total of 142 current and former student members anonymously completed the survey (a 71% response rate). It is assumed that some of the student members who participated in the qualitative interviews also completed the anonymous survey. Respondents completed a questionnaire that contained 29 Likert-type items about their attitudes and feelings *before* their experience with *Streetlight* and the same kinds of questions about their attitudes and feelings *at the time they completed the survey*. All item scores ranged from 1=*strongly disagree* to 5=*strongly agree*. Two single items asked whether the respondent had/has a *positive appreciation of life* and about the importance of *service as a strong core value in life.* A principal component factor analysis with varimax rotation on the 27 remaining questions referring to attitudes and feelings *before* participating in *Streetlight* resulted in a 4-factor solution (see Table 1).

Table 1. Survey Factors[a] and Chronbach's Alpha

Factors, items, and content	Chronbach's Alpha	
	Before *Streetlight*	Present
1. Understanding the experience of a chronic/terminal illness (9 items) *Before Streetlight* "I understood the psychosocial and spiritual challenges of a chronic or terminal illness." *Present* "I understand the psychosocial and spiritual challenges of a chronic or terminal illness."	.93	.80
2. Emotional capability to understand and cope with end-of-life issues (6 items) *Before Streetlight* "I felt emotionally capable of coping with death and dying." *Present* "I feel emotionally capable of coping with death and dying."	.92	.83
3. Communication skills (5 items) *Before Streetlight* "I had good communication skills (listening and talking) in the following settings…interacting in a team setting." *Present* "I have good communication skills (listening and talking) in the following settings…interacting in a team setting."	.85	.80
4. Understanding and respecting people from different backgrounds (7 items) *Before Streetlight* "I had a well-formed respect, appreciation, and understanding of people from a different socioeconomic level than my own." *Present* "I have a well-formed respect, appreciation, and understanding of people from a different socioeconomic level than my own"	.89	.88

[a]All factors were created by computing the average of their respective items.

The first factor attempts to capture an *understanding of the experience of a chronic/terminal illness.* The 9 items inquired about the following constructs: (a) understanding the psychosocial and

spiritual challenges faced by a people living with a chronic or terminal illness (e.g., I understood/understand the psychosocial and spiritual challenges of a chronic or terminal illness; I appreciated/appreciate the psychosocial and spiritual challenges faced by a teenager living with … cancer, cystic fibrosis, chronic illness, etc.); (b) empathy for people living with life-limiting illnesses; (c) experiencing someone close to their own age who died or was expected to die; (d) confidence to help patients; and (e) understanding of the healthcare system. The reliability coefficient Cronbach's alpha was .93 for the responses capturing attitudes and feelings before volunteering with *Streetlight*. A reliability coefficient Cronbach's alpha of .80 was obtained for responses pertaining to today's experiences.

The second factor was designed to measure the *emotional capability to understand and cope with end-of-life issues*. The 6 items asked whether respondents were/are capable of understanding and coping with death and dying, pain and suffering, and the decision to reject healthcare treatment (e.g., I felt emotionally capable of coping with … death and dying, pain and suffering). Cronbach's alpha was .92 (before *Streetlight*) and .83 (present).

The third factor, *communication skills*, consisted of 5 items that inquired about the members' skills to interact and communicate (both listening and talking) with strangers, healthcare workers, someone ill or in pain, etc. Cronbach's alpha was .85 (before *Streetlight*) and .80 (today). Sample items are "I had/have good communication skills (listening and talking) …in a team setting or …with a patient's family or guardian."

The fourth factor, *understanding and respecting people from different backgrounds*, comprised 7 items and inquired how much participants agreed that they had/have a well-formed respect, appreciation, and understanding of people from a different socioeconomic background, race, religion, culture, etc. Sample items are "I had/have a well-formed respect, appreciation, and understanding of people … of a different religion than my own …with extreme religious zeal (or absence of any religious affiliation) …of a different race." Cronbach's alpha was .89 (before *Streetlight*) and .88 (present).

The *experienced transformation* as a consequence of volunteering with *Streetlight* was measured by the average of 3 items (i.e., My volunteer experience with *Streetlight* was transformative for me … personally, spiritually, professionally). Cronbach's alpha was .61.

To assess the *number of years volunteering with Streetlight*, respondents were asked to check all the years (from 2006 to 2012) that they had volunteered with *Streetlight*. Control variables consisted of age (ranging from 1=*18-20 years* to 6=*34 years or older*), race (0=*nonwhite*, 1=*white*), and sex (0=*male*, 1=*female*).

Quantitative analyses and results.

As depicted in Table 2, paired sample *t*-tests showed that reported changes from before volunteering with *Streetlight* to now were all statistically significant with relatively large effect sizes as assessed by Cohen's *d*, corroborating Hypothesis 1. According to Cohen (1992), effect sizes greater than .8 are considered large, and effect sizes of around .5 are deemed medium in size. Respondents reported the greatest average gains in their ability to understand the experience of a chronic or terminal illness, understand and emotionally cope with end-of-life issues, and communicate with others. They felt that they were now better able to understand and respect people from different backgrounds than themselves and that they had a greater appreciation of life than

before their *Streetlight* experience. In addition, they reported that service was now an even stronger core value in their lives (a score of 4.80). It should be noted that the mean score for this item was already close to the maximum (4.40 out of 5) before their *Streetlight* experience.

Table 2. Comparisons of Means between Reported Attitudes and Feelings before the Experience with *Streetlight* and Now; Paired Sample T-Tests

	Before *Streetlight*		Now		Paired *T*-test		Cohen's	Rank order stability		
Dependent Variables	*M*	*SD*	*M*	*SD*	*t*	*p*	*d*	*r*	*p*	*N*
Understanding the experience of a chronic/terminal illness	3.07	.97	4.67	.36	18.51	.000	1.58	.07	.447	137
Emotional capability to understand and cope with end-of-life issues	3.17	.99	4.57	.43	16.73	.000	1.43	.25	.004	137
Communication skills	3.54	.77	4.61	.39	16.76	.000	1.43	.32	.000	137
Understanding and respecting different kinds of people	4.03	.70	4.66	.40	11.34	.000	.97	.40	.000	137
Positive appreciation of life	4.07	.87	4.85	.36	10.00	.000	.87	.13	.127	134
Service as a strong core value in life	4.40	.85	4.80	.44	5.65	.000	.49	.32	.000	136

Interestingly, the rank order stability coefficients of those variables were not particularly high, indicating that some respondents felt they had changed considerably more than others. The stability coefficient for the variable that recorded the greatest average change (understanding the experience of a chronic or terminal illness) was so low as to be insignificant (r=.07, p=.45). Similarly, the before and after *Streetlight* correlation for appreciation of life was not significant (r=.13, p=.13). The greatest rank order stability was found for understanding and respecting people from different backgrounds (r=.40, p<.001), followed by communication skills and the importance of service (both r=.32, p<.001) and the emotional capability to understand and cope with end-of-life issues (r=.25, p=.004).

Bivariate and multivariate regression analyses were conducted to investigate possible predictors for positive change and the overall experience of personal, spiritual, and professional transformation (see Tables 3 and 4).

Table 3. Bivariate Correlations between Changes from before *Streetlight* to Now and Years in *Streetlight*, Change in Service-Orientation, and Demographic Control Variables; Pearson's Correlation Coefficients

	Positive change in …								
	Understanding illness	Emotional capability to cope with end-of-life issues	Communication skills	Understanding different kinds of people	Positive appreciation of life	Experienced transformation	*M*	*SD*	*N*
Years in *Streetlight*	.22*	.19*	.23**	.11	.08	.15†	2.64	1.23	133
Positive change in service-orientation	.25**	.23**	.30***	.35***	.21*	.21*	.40	.82	136
Age	.13	.07	.04	.11	.04	-.08	2.22	.81	134
Race (1 = White)	.19*	.05	.05	.11	.07	-.16†	.50	.50	141
Sex (1 = Female)	-.09	-.03	-.08	.02	.07	-.01	.59	.49	132
M	1.60	1.40	1.06	.63	.78	4.66			
SD	1.01	.98	.74	.65	.90	.46			
N	137	137	137	137	134	134			

† $p < .10$; * $p < .05$; ** $p < .01$; *** $p < .001$

Table 4. Effects of Years in *Streetlight* and Change in Service-Orientation on Changes from before *Streetlight* to Now; Multivariate OLS Regression Analyses with Selected Controls

	Positive change in …											
	Understanding illness		Emotional capability to cope with end-of-life issues		Communication skills		Understanding different kinds of people		Positive appreciation of life		Experienced transformation	
Independent Variables	b	β	b	B	b	β	b	β	b	β	b	β
Years in *Streetlight*	.17	.21*	.15	.19*	.14	.23**	.07	.13	.07	.10	.06	.16†
Positive change in service-orientation	.29	.24**	.27	.23**	.27	.30***	.27	.35***	.23	.21**	.11	.21*
Race (1 = White)	.31	.15†	-	-	-	-	-	-	-	-	-.18	-.21*
Adjusted R^2	.10		.07		.13		.12		.04		.09	
N	132		132		132		132		129		132	

Note. Age and sex did not have a significant effect on any of the dependent variables.
† $p < .10$; * $p < .05$; ** $p < .01$; *** $p < .001$

As predicted in Hypothesis 2, an increase in service-orientation (assessed as the difference between service-orientation now minus service orientation before *Streetlight*) was directly related to a reported positive change in all of the variables as well as greater reported personal, spiritual, and professional transformative experiences. Years in *Streetlight* was also positively related to all of the dependent variables (Hypothesis 2), except change in understanding and respecting of individuals from different backgrounds and positive appreciation of life, for which respondents reported less overall change. Among the control variables, only race had any significant effect. In comparison to non-whites, whites tended to report a greater positive change in understanding the experience of a chronic or terminal illness but less transformation as a consequence of volunteering with *Streetlight.* Age and sex were unrelated to all of the dependent variables. The independent variables in the multivariate regression models explained between 4% (for positive change in appreciation of life) and 13% (for positive change in communication skills) of the variation in the dependent variables.

Discussion

The *Streetlight* experience expands its student members' comfort zones and ease with which they relate with the patients. The increased confidence in working with chronically ill and dying youths could have potential positive impacts on the rapport they build with future patients and their families. In a study designed to expand palliative care to underserved patient populations, researchers found that a grassroots movement of revolutionary individuals is the most significant element needed for healthcare improvements (Byock, Twohig, Merriman, & Collins, 2006). Adolescents and young adults with terminal illnesses are uniquely challenging for healthcare providers and a holistic approach is necessary (Cohen-Gogo et al., 2011). Contro, Larson, Scofield, Sourkes, and Cohen (2004) reported concerns regarding pediatric palliative care, indicated family members' desire for compassionate delivery of care, and urged improved education for all staff members. The aforementioned studies underscore the dearth of direct patient contact opportunities in pre-medical and pre-healthcare professional educational settings.

The *Streetlight* program director's influence and vision have extended beyond the inception of *Streetlight,* and the effects of her leadership continue to ripple throughout the program. Most participants attributed interactions with the director as having positively affected their program experience, career aspirations, and/or personal lives. Focused meetings at the beginning of shifts, social functions with patients, and outside social activities for members hosted by the director fostered cohesion and led to the participants' mirroring of the director's passion for *Streetlight*. In addition, the amount of time participants spent volunteering usually exceeded the minimum program requirements and credit for community service.

Participants reported increased self-awareness and realizations about life and death. They felt transformed by the vulnerability of connecting with the *Streetlight* patients; most of whom die before adulthood. The student members' relationships with themselves were expanded by their witnessing of patients' struggles and fortitude. Their evolving perspectives of self in relation to others informed their relationships with patients, their families, and other *Streetlight* members. Participants discovered new insights about their career callings, and their experiences clarified and solidified their career plans. Many student members reported commitment to pursue medical or healthcare education as a result of participating in the program.

Participants also credited their involvement in the *Streetlight* program with significant personal growth. The relevance of spirituality, an appreciation of the value of life, and the

importance of emotional connections were predominant themes in the discussions of the impact of *Streetlight.* In the quantitative survey, student members reported significant gains in empathy, communication skills, the importance of service, understanding and respect for people from different backgrounds, understanding and coping with end-of-life issues, and appreciation of life, through their experiences with *Streetlight*. Those who had volunteered with *Streetlight* longer and whose service-orientation had become stronger compared to before *Streetlight* tended to report the greatest gains in the above variables and also greater personal, spiritual, and professional transformative experiences. The only exceptions were the insignificant relations between years in *Streetlight* and reported positive changes in understanding and respecting people from different backgrounds and positive appreciation of life. Overall, the findings indicated that *Streetlight* had a profound effect on the student members. The reported positive changes tended to be greater for those who had volunteered longer with *Streetlight* and became more service-oriented through their experience with *Streetlight*. Age, by contrast, had no effect on any of the dependent variables. This suggests that it was not age-related maturation that elicited those positive changes rather the participants' volunteering experience with *Streetlight.* The longer they volunteered and the more dedicated they became to service, the more they learned about the experience of illness, dying, end-of-life issues, communication, diversity, and appreciating life.

Streetlight offers pre-medical and pre-healthcare professions undergraduate students the opportunity to address the unique challenges and needs of an exceptionally vulnerable population; these teachings can inform future interactions with patients. Establishing and integrating a program such as *Streetlight* into medical educational contexts could be effective in enhancing palliative care for adolescents and young adults, who are dealing with severe illnesses and the prospect of dying at a particularly vulnerable time in their lives. The program also provides much needed support to the patients' families who face the premature death of a loved one.

Limitations

There are several limitations to be noted. With a retrospective design, it is possible that student members' recollections either underestimated or overestimated the experienced gains. Future research should employ a prospective design to assess the actual differences in attitudes and feelings between before and after volunteering with *Streetlight*. Additionally, due to self-report of the subjective experiences of *Streetlight* members, there may be a social desirability bias in participants' responses.

Future program evaluation and impact studies could be conducted where a requirement of participation in the *Streetlight* program would include participation in the research project. Future research may focus on randomized controlled trials to examine the effectiveness of this program vis-à-vis other palliative care models. Longitudinal studies could explore the long-term impacts and gains of *Streetlight* participation on student members after entering professional medical or healthcare fields. Finally, it may be beneficial to conduct research to enhance understanding of the experience of palliative care from the patients' and families' perspectives (e.g., see Larson & Larson, 2002) to help determine the impact that *Streetlight* has had on them.

Conclusion

Results from this study provided evidence of student members' personal, spiritual, and professional transformation. The *Streetlight* program experience equipped participants with a more empathic, compassionate, and caring perspective that they can apply when working with patients

who are lonely and in pain and with family members who need support. Many participants described the initial awkwardness and fear they felt about entering patients' rooms, before having participated in *Streetlight.* The program expanded the comfort zone and ease with which these future medical and healthcare professionals could relate with their patients. The increased confidence in working with dying patients is likely to have positive impacts on the rapport they will build with patients and their families. Given the apparent benefits to past and current *Streetlight* student members who participated in the study, teaching hospitals may consider providing for their pre-medical and pre-healthcare students an educational opportunity within a palliative care program such as the *Streetlight* model.

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