The Family Story Project: Narrative, Ethics, and Community Collaboration Between Ronald McDonald House of Durham Families and Pre-Health Undergraduates

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ABSTRACT

The Family Story Project (FSP) brought together families at the Ronald McDonald House of Durham (RMHD) and pre-health undergraduates to co-construct narratives and visual portraits about family experiences. FSP shows that narratives can be rewarding for families and offer formative, skill-building experiences for pre-health undergraduates. FSP also demonstrates the ethical complexities surrounding community-university partnerships in health contexts, particularly with vulnerable populations such as children.

Keywords: medical humanism, illness, writing partnerships, children

INTRODUCTION

The Family Story Project (FSP), 2011-2015, formed a community-university partnership around health, writing, and photography. Pre-health undergraduates collaborated with families at the Ronald McDonald House of Durham (RMHD) to co-create narratives and photographic portraits about family experiences. The Family Story Project yielded benefits and ethical challenges. This case study situates the FSP within relevant literature, describes FSP structure, and identifies lessons learned.

LITERATURE REVIEW

Health-related community-university partnerships have contributed positively to public health (Coulter et al., 2016) and have enhanced pre-health undergraduate experiences (Kayser, 2017). Many health-related partnerships involve writing, such as community poetry healing workshops (Walker, 2016), written reflections about elderly nutrition service learning (Roofe, 2012), and literature reviews informing public-health education of beauty-salon employees (Türk, Çiçeklioğlu, Mermer, & Durusoy, 2014). Community-related writing empowers students and enhances critical-thinking and cultural competencies (Schmidt & Brown, 2016).

The Family Story Project integrated writing as reflection, method, and product, as RMHD families and FSP undergraduates co-created illness narratives about family experiences. Illness narratives, though quite varied, involve narrative accounts of experiences and facilitate increased awareness and sense-making (Kaplan-Myrth, 2007). Narrative helps construct the self in relation to the world (White, 1980; McAdams, 1997). Composing illness narratives helps people create meaning around illness (Kleinman, 1988), and can improve symptoms and overall health (Pennebaker, 2000). Illness narratives confer agency (Frank, 2004) and facilitate coping (Morris, Simpson, Sampson, & Beesley, 2015). They also forge human connections (Hydén & Brockmeier, 2008), especially in isolating contexts such as chronic pain (Dysvik, Natvig,

& Fumes, 2013) and chronic pediatric care (Nutting, 2015).

Illness narratives not only benefit patients, but reflect and shape family cultures (McIntosh, Stephens, & Lyons, 2013), and can positively influence family health promotion, family legacies about illness, and coping (Christensen, 2004; Toyama & Honda, 2016). Family illness adaptation can also be understood through children's narratives (Popp, Robinson, Britner, & Blank, 2014). Illness narratives authored or co-constructed by children reveal children as active agents in their health care and offer health-care providers unique insights (Rindstedt, 2016; DasGupta, 2007). Learning about and with narratives also benefits health providers by cultivating skills central to patient-centered care such as listening, empathy, ethics, and self-reflection (Charon, 2006; Guillemin & Gillam, 2015). Accordingly, narrative epistemologies are being increasingly integrated in medical and pre-health curricula (Lam, Lechner, Chow, Chiu, & Chiu, 2015; Ousager & Johannessen, 2010).

While illness narratives offer many benefits, they also create risk. They can promote misinformation (Farkas, 2013), and reinforce deleterious, hegemonic expectations about how people should, or should not, respond to illness (Sontag, 1978). When misused, illness narratives can broaden provider power over patients (Brody & Clark, 2014). Children's health narratives carry particular risks around consent, privacy, confidentiality, and agency (Honeyman, 2016). Most children rely on proxy consent for narrative participation, but researchers recommend children share consent provision with parents (Rose, 2017).

THE FAMILY STORY PROJECT STRUCTURE

Any community-university partnership should be built around an ethical framework that includes effective preparation, shared benefits, mutual respect, and trust (Sadler et al., 2012). Such a framework is particularly crucial with health-related partnerships such as FSP.

The Family Story Project structure consisted of a primary partnership between Ronald McDonald House staff and a Writing Studies faculty member in the Duke University Thompson Writing Program. FSP partners also included the undergraduate pre-health advising network and the Duke University Medical School, both of which helped advertise FSP opportunities.

Each August, five or six pre-health sophomores were selected through a competitive application process based on overall GPA, performance in first-year writing, references, community-engagement experiences, and a letter describing what they hoped to learn from the FSP. Preference went to those with Spanish fluency. Sophomores were targeted because they declare majors during this pivotal year, often have more time than upper-division students, and have requisite writing capacities from first-year writing. FSP also recruited four undergraduates each year who were interested in and experienced with portrait photography.

Once selected, Family Story Project undergraduates visited RMHD in pairs (one FSP writer, one FSP photographer) each month across the academic year, co-constructing narratives and photographs with families. Ronald McDonald House staff facilitated introductions. Families used informed consent and media releases (in English or Spanish) to decide about participation and whether to make narratives more public through the RMHD newsletter and/or an annual FSP booklet given to participating families and the RMHD. Narratives focused on the child's illness, the family's experience, and the Ronald McDonald House of Durham. While FSP undergraduates anticipated composing in Spanish according to family preference, and then, if needed, translating more public narratives into English, all of the families preferred English narratives. More public narrative versions removed as much identifying information as possible and families could

choose whether to include photographs. Narratives were provided, with family consent, to the RMHD, who then decided which narratives to feature in their monthly newsletters. Across four FSP cycles, 72 RMHD families collaborated with 26 pre-health undergraduates and 10 undergraduates interested in photography.

Preparatory training for Family Story Project undergraduates consisted of Ronald McDonald House organizational information, cohort building, simulated family conversations, and an RMHD visit. Training also introduced illness-narrative scholarship and examples, addressing aims, as well as narrative ethics, power, privacy, and identity. Across the year, a co-curricular seminar brought FSP undergraduates and, as available, other FSP partners, together over dinner for two hours each month. The first hour consisted of a guest lecture or text discussion on such topics as hospice, pediatric oncology, health humanities, and culture and medicine. The second hour included verbal debriefing, reflective writing, and facilitated peer writing workshops on narratives-in-progress. These workshops generated peer feedback on structure, tone, representation, word choice, perspective, organization, clarity, privacy, and audience. Productive workshops were feasible because FSP undergraduates already had strong writing and peer-feedback skills from first-year writing. Narratives went through multiple revisions, with feedback from peers, the FSP faculty director, and RMHD families, who collaborated through in-person meetings, phone conversations, or email. RMHD families provided final approval on the narratives.

FSP also integrated near-peer mentorship by pairing pre-health sophomores with third-year medical students at the Duke University School of Medicine (third-year medical students were targeted because they have more curricular time). The mentor opportunity, which also broadened FSP's potential spread of effect, was advertised through a listserv, and interested medical students sent a brief statement to the FSP director outlining their interests in mentorship and narrative. Mentor-mentee pairs met for coffee or lunch once or twice each semester to discuss medical conditions related to the narratives and the role of narrative in medicine.

FSP assessment consisted of a mixed-methods approach and evolved across the four cycles. Assessment for the first two years included debriefing with RMHD staff and undergraduate participants, and written reflections by FSP undergraduates. An anonymous family-satisfaction survey was added in the third year, mailed with a stamped return envelope to participating families from years three and four. Across all years, FSP undergraduates could contribute through IRB-approved informed consent their de-identified written reflections and those in the latter three years could also complete an IRB-approved, end-of-year, anonymous survey. RMHD families were not part of the research, although family satisfaction surveys were. Lessons learned emerge from the following data: two years of family-satisfaction surveys (N=9; 24% return rate); written reflections by undergraduates who consented to participate in the research (N=17; 47% consent rate); and undergraduate surveys (N=12; 33% consent/return rate).

LESSONS LEARNED: BENEFITS

The FSP yielded several positive impacts: Gratitude, Narrative Benefits, and Writing Growth.

Gratitude

Gratitude is a valuable contributor to subjective well-being, health, and quality of life (Tian & Huebner, 2015; Karns, Moore, & Mayr, 2017), and has positive impacts on people adjusting to illness (Toussaint et al., 2017). Gratitude emerged as the overriding affect from families and FSP undergraduates. Families expressed gratitude for sharing their stories, for the interactions, and for the stories themselves:

"Please tell B--- and L--- how grateful we are. [They] were so kind and … patient and listened to his very long story. An event we will remember."; "Thank you for everything." Gratitude also pervaded FSP undergraduate comments: "The [FSP] has been such a blessing to me. I have enjoyed getting to know the families … it has been such a privilege to be able to listen to their stories"; "I'm so thankful that I'm learning how to be a better listener and communicator through this program, and that I'm helping people share their stories that need to be heard." That several families and FSP undergraduates maintained contact beyond their collaborations (Comer & Hong, 2015) suggests that positive emotions such as gratitude can cultivate longer-term connections from community-university partnerships.

Narrative Benefits

The benefits ascribed to illness narratives (see Literature Review) also manifested for FSP participants. Suggesting that the narrative process was itself rewarding, families conveyed the highest satisfaction with the FSP collaborations as well as the narratives and portraits (Figure 1). They conveyed joy and happiness from the narrative experience: "It was a really fun experience"; "I was very happy to have my son and I a part of this project." Families indicated that the narratives would contribute to family legacies: "Thank you so much for this awesome commemoration of my daughter and our family's struggles." Several families lost children during or after the collaborations; one such parent described the narrative as "something I will cherish forever."

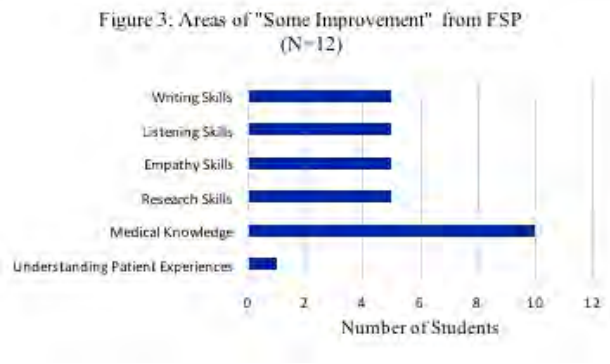
FSP undergraduates found that their Family Story Project experiences increased their own resilience: "FSP has given me perspective. An Orgo test or a bad grade doesn't seem so bad, since I haven't been unfairly born with a defective heart or retinoblastoma." Asked to identify areas of greatest improvement (Figure 2), the majority of FSP undergraduates indicated understanding of patient experiences (11), listening (9), and empathy (7). FSP undergraduates anticipated these skills would enhance their approach to health care: "[B]eing able to converse with families … is the most useful form of 'research' that will shape how I interact with patients in the future." Listening emerged as especially valuable: "I'm also gaining experience as someone who is simply there to listen."

FSP's narrative dimension augmented the pre-health curriculum: "Just as all premedical students must take organic chemistry … I believe experiences like the FSP should also be required … [O]ur premedical courses … cannot teach us … about understanding the experience of illness—how the illness affects the patient's and family's lives." Several undergraduates reconnected with fading passion: "It's amazing how well timed my visits to the RMHD are. They always occur when I begin to feel particularly disenchanted with the pre-med way of life." FSP's narrative approach also sparked career reflection: "I was so certain I wanted to be a surgeon, but

I wonder now how I would like a specialty that's more interactive."

Writing Growth

The majority of FSP undergraduates identified strong improvement or some improvement in writing (N=9; Figures 2 and 3). Writing growth seemed primarily to be meta-cognitive. Students discovered intersections between writing and critical thinking: "[FSP] has improved the way I write because it causes me to focus on other people's opinions and perspectives rather than my own"; "[W]riting down thoughts paves the way for conceiving … deeper thoughts." Students gained heightened consideration of readers: "The main way my writing has benefitted from [FSP] is being more cognizant of my reader." This student specified that awareness of reader impacted her approach to sentence length, organization, and background information. Finally, FSP enabled students to discover joy in the writing process: "[FSP] has given me the chance to enjoy the writing process, as it combines a passion for a future I wish to obtain in medicine with a rewarding experience of capturing the details of the lives of people."



LESSONS LEARNED: CHALLENGES

FSP also surfaced ethical challenges: Conflicting Aims; Emotional Dimensions; Institutional Complexities; and Sensitive Information.

Conflicting Aims

Community-university partnerships involving writing often exhibit competing priorities with authorship, stakeholders, purpose, and audience (Rose & Weiser, 2010; Taggart, 2007). For FSP, the time-intensive nature of illness made collaborations challenging to schedule and maintain. If families left RMHD, collaborations continued via email, which removed in-person interactions and caused delays. Across time, some families shifted priorities and narratives-in-progress lapsed. FSP undergraduates simultaneously honored family ownership but used pronouns suggesting proprietorship: "I hope my story reflects the utter strength of this little girl and her mother." These sorts of comments and the logistical fluctuations raised ethical questions about purpose: Who were FSP narratives serving and for what ends?

Even consistent collaborations encountered challenges because of RMHD newsletter commitments. The RMHD newsletter provides outreach (to families, volunteers, staff, board members, and patrons), so newsletter versions integrated family impressions about the Ronald McDonald House of Durham. Coupled with newsletter word count restrictions, this focus impacted tone, structure, and content, morphing some narratives into what seemed a template instead of an individualized account.

Emotional Dimensions

Emotions are an important but under-researched aspect of community-university partnerships (Ross & Stoecker, 2016). Most FSP undergraduates identified empathy as a capacity where they saw strong or some improvement (Figures 2 and 3). The following comment reflects this element:

> We met a woman once who had given birth to three premature babies, and she was pretty much at the RMHD by herself … [She] proceeded to tell her story for at least a full hour … This experience reminded

> me of the importance of just being there to listen, especially [when] circumstances can often feel isolating.

Sometimes these emotional connections resulted in anxiety or mourning. While FSP undergraduates discussed emotions during the co-curricular seminar, this could not substitute for mental-health expertise.

Institutional Complexities

The Ronald McDonald House posed unique challenges for a health-humanities collaboration because of its multi-faceted relationship with health. Founded in 1974, and now comprised of more than 360 locations in over 40 countries, RMH privileges family-centered care (Rubin & Franck, 2017), mitigating psycho-social family stressors by providing affordable, comfortable living spaces, home-cooked meals, and community interaction (Haski-Leventhal, Hustinx, & Handy, 2011; Duncan & Blugis, 2011). Still, the McDonald's brand is negatively correlated with health (Alhéritière, Montois, Galinski, Tazarourte, & Lapostolle, 2013), and non-governmental organizations have in the past exploited images of vulnerable people (Fehrenbach & Rodogno, 2015). These institutional tensions can impact perceptions about corporate social-responsibility (Brønn, 2006) and community-university partnerships.

Another institutional challenge involved Duke University, which is an elite, private university comprised of many undergraduates of privilege. Although socio-economic status, race, and ethnicity varied across FSP undergraduates and RMHD families, FSP undergraduate reflections often demonstrated "othering language," which emphasizes self-perceptions of difference (Seider & Hillman, 2011). Such language correlates with the binarism that often emerges around illness, such as healthy versus unhealthy (Frank, 2004). One can see this sort of othering and binarism in the following FSP undergraduate reflection:

> I'm so blessed to lead the easy, privileged life I do. I want to use my education and my passion to help girls like [the two I spoke with] receive the necessary care and compassion that enables them to keep on smiling.

Sensitive Information

Foremost among the FSP's ethical complexities, though, was the matter of sensitive information about children: "Today's visit was one of the harder ones that I've experienced, and it once again reminded me that what I learn from the families … is confidential and private information." Parents provided consent and decided whether to make narratives more public. While some collaborations included children in drafting or decision making, many did not because of a child's age, capacities, or availability. Thus, the Family Story Project opened risk for children later disagreeing with parents' proxy consent decisions.

CONCLUSION

FSP had positive impacts with gratitude, narrative benefits, and writing growth. FSP participants also faced ethical challenges, including conflicting aims, emotions, institutional contexts, and sensitive information. More research is needed into the emotional dimensions of community-university partnerships and the longer-term impacts of undergraduate pre-health narrative programs. The Family Story Project illustrates the importance of close mentoring and ethical responsibility with health-related community-university partnerships.

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