

A Day in the Life of a Young Person with Anxiety: Arts-Based Boundary Objects Used to Communicate the Results of Health Research

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Abstract: In this article we outline the creation of boundary objects as just one of the means to communicate the results of the *Youth's Voices* research study that sought to understand young people's experiences of living with anxiety. Fifty-eight young people living with anxiety took part in open-ended interviews complemented by photovoice. As one knowledge translation strategy, themes emerging from the data were transformed into boundary objects of a series of video vignettes representing dance interpretations of the themes. The video vignettes revealed meaningful interpretations of the young people's experiences, creating the potential for enhanced empathy and understanding, and reduced stigma for young people living with anxiety. The creation of boundary objects affords the opportunity to communicate the experiences of young people living with anxiety to a wider audience of policy makers, health care practitioners, researchers, as well as the general community.

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1. Introduction

Health researchers have steadily been developing new ways for promoting the engagement of research participants through highly interconnected research communities of practice, or (R)CoPs (FUMAGALLI, RADAELLI, LETTIERI, BERTELE & MASELLA, 2015). Within such health (R)CoPs, qualitative participatory research methods are often used towards enhancing meaningful engagement and enabling participants to more authentically express their experiences with illness and navigating health systems (HICKS et al., 2012; WOODGATE, ZURBA & TENNENT, 2017a). As an extension of this practice, and towards promoting deeper and more nuanced understandings of the lived experiences of participants, novel arts-based approaches to knowledge translation (KT) are increasingly being used as evocative methods for communicating the results of health research (BOYDELL, GLADSTONE, VOLPE, ALLEMANG & STASIULIS, 2012; BOYDELL et al., 2016; DAYKIN, GRAY, McCREE & WILLIS, 2016). Such creative approaches can be especially effective for communicating experiences around health issues that are consistently challenged by fear and stigma, such as issues around mental health (BOYDELL, 2011; RAVELIN, KYLMÄ & KORHONEN, 2006). BOYDELL et al. (2016) talk about arts-based health research as "boundary crossing work" that involves "incorporating humanities, social, and medical sciences [and] is recognized as representing a paradigm shift whereby KT is seen as a creative, complex, and dynamic process, rather than one that is passive or linear" (p.12). [1]

In this article we document the methodological process of transforming scientific results from a research study into an artistic creation. Specifically, the focus of this article is the boundary-crossing KT work achieved through collaborative creation of the "boundary objects" emerging from a health (R)CoP brought together through a project led by WOODGATE titled "Youth's Voices: Their Lives and Experiences of Living with an Anxiety Disorder" (*Youth's Voices*). Boundary objects are items that are "valued on both sides of the boundary and provide a site for cooperation, debate, evaluation, review, and accountability" (CASH & MOSER, 2000, p.115). The aim of boundary crossing KT work and the creation of boundary objects was to communicate the experiences of young people living with anxiety to a wide audience of policy makers, health care practitioners, researchers, and people from the general community. The rationale behind crossing such boundaries was to generate, through artistic representation (i.e., the boundary object), tacit experiences of what it is like to be a young person living with anxiety, in turn creating the potential for enhanced empathy, new understandings, and the diminishment of stigma. The boundary objects created were a series of video vignettes featuring five main themes from the Youth's Voices project. Through qualitative data analysis of the project's main data (i.e., interviews and photographs), themes depicting a day in the life of a young person living with anxiety were developed. The creation of the vignettes involved WOODGATE and her research team, artistic direction by the choreographer Philippe JACQUES, videographers Jérémie and Janelle WOOKEY from Wookey Films, and performance by dancers of the Royal Winnipeg Ballet (RWB) Aspirant Program. We first provide a description of boundary objects with a focus on arts-

based boundary objects and knowledge translation in the context of health research (Section 2). The methods used for the *Youth's Voices* research study are then described (Section 3). The scientific results emerging from the *Youth's Voices* study as well the process of transferring the results into an artistic creation (i.e., video vignettes) are illustrated (Section 4), leading to a discussion (Section 5) and conclusion (Section 6). [2]

2. Background

2.1 Context for boundary work

Anxiety disorders are one of the most prevalent mental illnesses affecting youth (POLANCZYK, SALUM, SUGAYA, CAYE & ROHDE, 2015). However, many families in Canada feel as though their challenges are not taken seriously and that resources are not in place to deal with the mental health issues of youth in the same way that they are in place to deal with other potentially life-threatening illnesses (CBC NEWS, 2016). Compounding the lack of resources for youth and their families is the stigma surrounding mental illness. In a qualitative systematic review of the best available evidence on the meanings young people assign to living with mental illness, WOODGATE et al. (2017b) revealed that young people would conceal certain aspects of their mental illness as well as avoid seeking help for fear of being stigmatized. This gap existing between the experiences of youth and their families requiring mental health services denotes the importance of boundary crossing work that needs to be done towards addressing stigma, building empathy and understanding, as well as improving the system of care. [3]

2.2 Boundary crossing, boundary objects, and health research

WENGER (2000) was one of the first to illuminate the significance of exploring boundaries towards understanding how knowledge is produced within CoPs. WENGER (p.227) explained how boundaries create connections and learning opportunities through being exposed to "foreign competences" and abstract thinking, and how boundary work promotes engagement (doing things together), imagination (understanding different roles), and alignment (understanding how activities affect processes beyond one's own engagement) within CoPs. The conceptualization of "boundary objects" was first presented by STAR and GRIESEMER (1989) as a way of framing material items and other forms of representations that "inhabit several intersecting worlds and satisfy the informational requirements of each of them" (p.393). In this seminal work, STAR and GRIESEMER elaborated on boundary objects as being "both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites" (ibid.). Boundary work and boundary objects are meant to transcend disciplinary fields (TROMPETTE & VINCK, 2009), and can establish and destabilize concepts and practices within communities (LEE, 2007). SAPSED and SALTER (2004) explained further how boundary objects are at once intentionally marginal (i.e., are meant to reach outside of centralized ways of knowing and communicating)

and are characterized by centrality (i.e., understood and related to more easily) within particular communities or parts of communities. [4]

Towards qualifying boundary objects further as a working concept, STAR (2010) explains how boundary work need not result in consensus. She also clarifies that the dialogical space created around a boundary and the boundary object itself can become scaled up or standardized resulting in a shift from boundary objects to "boundary infrastructures." Through new infrastructures for understanding and standardization boundary objects can catalyze meaningful connections within CoPs (ZURBA & BERKES, 2014), as well as between them (LEE, 2007; RATHWELL & ARMITAGE, 2016; ZURBA & BERKES, 2014; ZURBA & FRIESEN, 2014), including with policy makers (BERG, 2002; GUSTON, 2001; ZURBA & BERKES, 2014). This can be applied not only to CoPs that share common ground, but also to disparate CoPs (PAWLOWSKI & RAVEN, 2000; PAWLOWSKI & ROBEY, 2004), including multidisciplinary (R)CoPs. Within the health field boundary objects have been found to link clinical, management, and service user worlds and create solutions for managing circumstances that are affected by interdependencies among groups (ALLEN, 2009). For example, FUJIMURA (1992, p.205) explored the use of boundary objects in the context of oncology and found that they were useful for understanding how representations were constructed and "held sacred," and how boundary objects made it possible to explore different kinds of representations. STAR (2010, p.603) illuminates that the materiality of a boundary objects is the consequence of action, and that they are defined pragmatically and not by their "thing-ness." Therefore, boundary objects can come in many different formats. For this project, WOODGATE and her research team focus on arts-based boundary objects in KT of health research towards providing further context for the collaborative work aimed at creating powerful representations of young peoples' experiences living with anxiety. [5]

2.3 Arts-based boundary objects and knowledge translation in health research

Arts-based boundary objects are commonly used in research fields such as education and geography (RATHWELL & ARMITAGE, 2016; SANDERS, 2006; ZURBA & BERKES, 2014), and are now increasingly being used in health research (BOYDELL, 2011; BOYDELL et al., 2012, 2016; RAVELIN et al., 2006). This use of art forms as boundary objects in health research is indicative of a new understanding of the importance of interpreting social realities in a way that is respectful of the dynamic, iterative, and complex nature of social systems and the interactions between researchers and stakeholders (QUINLAN, 2009). Dramatizations, including movement and music, are particularly powerful for communicating emotions and can awaken critical consciousness and promote communication and resilience across groups that might otherwise have difficulty understanding one another (BOAL, 1998; CLIFT, 2014; HOWE, 2009; QUINLAN & DUGGLEBY, 2009). Therefore, the arts can be used as a community intervention creating supportive environments and potentially opening pathways for understanding different epistemologies (ROBERTS et al., 2011; WAINWRIGHT & RAPPORT, 2007). Aesthetic language can be particularly

effective for powerfully expressing the experiences of people involved in health systems (QUINLAN & DUGGLEBY, 2009), which are often dominated by Western scientific interpretations (BOYDELL et al., 2016; CLIFT, 2014). [6]

Participants often feel as though they are contributing to society through their involvement in health research and KT (WOODGATE, TENNENT & ZURBA, 2017c). Arts-based approaches are particularly effective for supporting participation and creating conduits for emotional connections and the delivery of messages that are deeply embodied and difficult to express through words alone (BOYDELL, 2011; BOYDELL et al., 2016; WOODGATE et al., 2017a). The creation of a "constructed event" or performance can be an especially powerful way to initiate collaboration between different groups around issues relating to health (QUINLAN, 2009). There however can sometimes be tensions in collaboratively creating art for KT where some members of a CoP (often those with a more academic background) might feel that the "fuzziness" of arts-based work is not rigorous, while others feel that it provides an open space for dialogue (BOYDELL et al., 2016). Such tensions can be mitigated through carefully defining the objective(s) of the arts-based component of the work, roles within the CoP, and expected outcomes at an early stage of the creative process (BOYDELL, 2011; NICOLINI, MENGIS & SWAN, 2012). Thus, engaging (R)CoPs in arts-based research and KT can require a careful examination of practices, relationships and willingness to identify ethical challenges (YASSI et al., 2016). This process is described within the context of the research and a KT project for the Youth's Voices study. [7]

3. Methods

3.1 Interviews with young people living with anxiety

The *Youth's Voices* study included 58 young people living with an anxiety disorder, who were between 10 to 22 years old at the time of the study and who were referred to anxiety programs at a variety of sites including hospital-based clinics in Winnipeg, Canada. The qualitative research design of hermeneutic phenomenology was used, as it afforded the opportunity to understand youth from their frames of reference and experiences of reality living with an anxiety disorder (VAN MANEN, 1990). Youth were selected by the maximum variation technique of purposive sampling and the research took a phased approach (SANDELOWSKI, 1995). First, each youth took part in an open-ended, face-to-face interview, which afforded them the opportunity to focus on the most salient and accessible aspects of their perspectives of living with an anxiety disorder. Open-ended interviews engaged the interviewees as knowledgeable "informants" about anxiety and encouraged detailed responses, facilitating the generation of new knowledge, and guiding subsequent interpretation (DARBYSHIRE, MacDOUGALL & SCHILLER, 2005). [8]

Use of photovoice complemented the second interview. Photovoice is a participatory method that involves co-researchers in taking photographic images to document and reflect on issues significant to them and how they view

themselves and others (SZTO, FURMAN & LAGNER, 2005; WANG & BURRIS, 1997; WANG & REDWOOD-JONES, 2001; WOODGATE et al., 2017a). At the conclusion of the first open-ended interview, the photovoice process was explained to youth. Each youth co-researcher¹ was given a digital camera and then asked to take pictures over the following three to four weeks that depicted their thoughts and feelings about what it is like to live with an anxiety disorder. Photovoice recognizes the importance of amplifying the voice to situated events and perspectives through photographs that give a sense of being there and seeing the setting and people first-hand (PATTON, 1990; SZTO et al., 2005). It is an especially effective strategy for youth living with an anxiety disorder, as it is an unobtrusive way of entering their worlds, and can give meaning to thoughts and feelings that are often difficult to express with words (BERMAN, FORD-GILBOE, MOUTREY & CEKIC, 2001; STRACK, MAGILL & McDONAGH, 2004; WOODGATE et al., 2017a). During the second open-ended interview, youth were asked to talk about what the photos meant to them in terms of living with anxiety. [9]

Interviews lasted from 30 minutes to 3 hours and were digitally recorded and transcribed verbatim to preserve their authenticity. Field notes were also recorded following the interviews towards recording the detailed context of the interviews. Youth were able to choose to stop the interview at any time. When probing youth for more detailed responses, care was taken to ensure that the young people were not distressed and that emerging themes were grounded in their experiences. Ethical protocols included review from the university ethics committee, written prior and informed consent from participants over the age of 18 and assent for participants who were minors, and an ongoing process of verbal consent throughout the stages of research. Families also received honoraria for their participation. [10]

3.2 Analysis

Data analysis occurred concurrently with data collection which provided the opportunity for youth to have ongoing input into theme development through an iterative research process and multiple interviews. Analysis involved identifying recurrent themes across participants and involved delineating units of meaning from the interview and photovoice data, clustering units of meaning to form thematic statements, and extracting themes (VAN MANEN, 1990). Thematic statements were isolated and extracted by selecting and highlighting sentences or sentence clusters that stood out as thematic of the various struggles and coping strategies experienced by youth and depicted the story of a day in the life of a young person with anxiety from start to finish. By formally linking the photographs to the corresponding interview data, the photographs served as graphical representations of the text-based findings, and contributed to a greater understanding of the youth's experiences of living with anxiety. WOODGATE and her research team met with a Youth Advisory Committee (YAC) that was created for the research study and comprised of co-researchers. The YAC provided

1 We use the term "co-researchers" instead of "participants" for our study to acknowledge the contributions made and the power that has been divested according to participatory research principles.

guidance to the research team about the themes that should be conveyed through KT initiatives and their suggestions of the types of KT strategies that could best convey those themes. Through the meetings, the YAC stated clearly and unanimously that they wanted people to achieve a deeper understanding of what it is really like to be a young person living with anxiety, and how anxiety affects their day-to-day lives. The YAC felt that these messages could best be represented through an arts-based KT strategy. [11]

4. Results

4.1 Themes

Five strongly emergent themes revealed different components of a day in the life of a young person with anxiety. The first theme is *Hiding the Struggle* and relates to how young people living with anxiety struggle with their sense of self, feeling they have to hide their anxiety and hide the pain that comes with living with anxiety. The following caption for a photographic image submitted by a co-researcher highlighted this theme, and became the narration for the corresponding vignette (as did the other quotes presented below).

Co-researcher (male, 13 years old): "If you study a person's face you can see a lot of things, stuff that might be there and stuff that might not be there, but you can see that I'm a little bit stressed a bit in that picture."

Interviewer: "What parts of it do you think show that you're stressed?"

Co-researcher: "Well my lips are quite straight considering, cause people don't go like [gestures smiling] all the time ... But it looks like everything, not in a gross way but like everything has gone, moved down, has been anchored down in, in my face and in my body cause my shoulders sag, my knees are like bent a little because it's like not wanting to stand up anymore." [12]

The second theme, *Fear of the Unknown* emerged from the data from many youth in the research project who described how seemingly everyday tasks, such as getting dressed for school, or putting your shoes on to walk out the door, can be much more difficult when you are living with anxiety. A co-researcher (female, 22 years old) described this in terms of the thoughts that often go through her mind when she is preparing to leave her home.

"Anytime I'm about to leave to put my shoes on I'm staring at that door, no the door is not even open, I ask myself should I even go, like what's the point, I don't want to go, like what's so important about going to work. Like and just and that mat, we've had that mat for so long ... Like it's like a dark hole." [13]

The third theme *Taking up Space*, relates to how young people living with anxiety, at times, can feel bombarded by the sights and sounds of everyday life and as a result, may isolate or limit themselves to certain places and spaces. Youth also shared that as a result of their anxiety they often felt that they were not good enough and therefore could not or should not *take up space*. As a coping

strategy, many of the co-researchers talked about how nature and the outdoors can help to rejuvenate them during these times. One co-researcher (female, 17 years old) framed this literally as being able to take up space in their environment.

"I feel it would just be nice to do something with a friend or even by yourself and just have like no noise or people or you know cars or honking or lights and just like be in the sun and be in the flowers, yeah just being and be able to breathe and not feel like constricted in any way and just like take up space. Like I hate that you can't take up space in the city. You're so confined and I saw this thing on the internet the other day where um how so often people especially women apologize for taking up space, like if you're sitting some place and you accidentally like you're too far, 'oh sorry' ... I feel like in nature you can literally spread your arms as far as you want and go out for miles and just like twirl around and not have to worry about bumping into somebody or tripping over somebody or hitting somebody and just like I don't know, I just think it would be so nice." [14]

The fourth theme *Feeling Different*, is based on how youth living with anxiety often feel judged and different from everyone else around them. This feeling of being different was described in the vignette as being related to having to take medication, but other reasons such as having to go see a doctor or seeking assistance in school were common in the data. Many youth talked about the stigma that they faced as a result of their anxiety. Another co-researcher (female, 17 years old) illustrated feeling different when explaining her photovoice image featuring the pills that she took every day (Figure1).

"When I took this [picture] I thought it looked really pretty, but it was a point when I was on a lot of medication. Not all of it was for my mental health. I mean a lot of it was, but some of it was just for like um to keep myself like not getting sick in the winter. But um, I remember showing my friends this and they would laugh and like 'huh huh you take so many pills,' and then I would look at it and be like I didn't think it was funny. Like oh, I do take a lot of pills ... As soon as it was pointed out to me how many pills I take it was like 'oh I do,' and then it kind of installed this like fear like what makes me so messed up that I need this much medication to make me better."



Figure 1: Feeling different [15]

The fifth and final theme is *Can't You See I'm Struggling?* This theme relates to how the burden faced by young people living with anxiety is heavy. Youth talked about how at the end of the day they can feel worn down by the weight of what they deal with in their day to day lives. This final theme also connected to the importance of encouraging people to reach out, to seek and offer support and to listen to the experiences of young people. Many co-researchers from the research project described their anxiety as a heavy backpack and submitted images of their school backpacks to represent this sentiment. Drawing on these findings, the analogy of the "backpack" was used throughout the vignettes as a way of connecting and showing continuity throughout the scenes. Another 22 year old female co-researcher described this feeling of struggling as carrying a very heavy backpack full of burdens:

"The anxiety almost, it's almost like you're crawling instead of just having that stroll to achieve whatever, you're almost crawling and, and almost scraping through the floor, like trying to get there ... 'Cause anxiety is like riding on your back almost, and you're like crawling and it's so heavy ... But it's just, I guess anxiety is that burden, the heavy, heavy backpack on you, it's full of things you don't even need but they are there." [16]

The arts, and specifically dance as a coping strategy, was a theme in the research. Many of the youth were involved in dance lessons and reflected on

dance as being an important outlet for emotions. For example, the following 11 year old co-researcher talked about dance and making her own choreography.

Co-researcher: "Actually one of my favorite [coping] techniques is I'm a dancer ... So after I breathe for a bit I would dance and I would kind of channel all my worry and I would kind of put it into a dance."

Interviewer: "And did you like choreograph it yourself then."

Co-researcher: "Yeah, I kind of just choreograph dances and then I just put everything into my dance." [17]

The importance of dance in the lives of many of the youth gave WOODGATE and her research team the assurance that pursuing interpretive dance as a KT strategy was an appropriate approach. [18]

4.2 Collaborative creation of the boundary object

4.2.1 Assembly of the creative team and initial decisions for knowledge translation

A core creative team was brought together by WOODGATE for the KT component of the *Youth's Voices* project. The core team included WOODGATE and her research team, youth co-researchers who were part of the youth advisory council (YAC), and consultants who were asked to join the team because of their creative expertise. Consultants included Philippe JACQUES, a choreographer and artistic designer who was asked to join because of his interest in human rights issues and experiences working with youth and choreographing dance for the RWB Aspirant Program², and Jérémie and Janelle WOOKEY from Wookey Films who were asked to join because of their experience with research-based videography and expertise in filming dance. [19]

WOODGATE summarized the effectiveness of participatory art-based approach that was used for exploring the co-researchers' experiences as:

"Artistic representation was an effective way for empowering young people to express how anxiety affected their day to day lives. For example, taking photographs allowed youth to express their thoughts and feelings in a way that may not have been possible for some using words alone. Such a creative process generated meaningful opportunities for the youth in this study to reflect and develop a deeper understanding of themselves and their relationships with the different people, places and systems of care and support." [20]

The research team then explored the various opportunities for arts-based dissemination of the project. After reviewing the various suggestions of the YAC and meeting with a number of production companies, the research team decided

2 The RWB Aspirant Program "is a full-time, intensive, post-secondary training program designed for advanced level classical ballet dancers who are making the transition from student to professional dancer" (<http://www.rwb.org/school/professional-division/programs/aspirant-program>) [Date of access: March 15, 2017].

that transposing the five themes into dance and using a series of video vignettes³ would be a unique and powerful approach to engaging the public in understanding *A Day in the Life of a Young Person with Anxiety*, the central recommendation of the YAC. The first meeting between WOODGATE and her researchers, and JACQUES and the WOOKEYs resulted in fruitful discussions and genuine commitment to the project.

"From the beginning, we realized that the most important thing was that we really understood Dr. Woodgate's research and the five themes selected. We wanted to make sure that all of our creative choices throughout the process were 100% driven by the research" (WOOKEY). [21]

Following this meeting, the selected photos and quotes representing the five themes of a day in the life of a young person with anxiety were shared with JACQUES who then came forward to WOODGATE and her research team with ideas for translating them into scenes. JACQUES, WOODGATE, her research team, and the YAC then worked iteratively towards developing the scenes that would make up the vignettes. The vignettes were narrated using quotes directly from interview transcripts and photovoice captions. This was an important aspect to ensure authenticity and that the voices of co-researchers were highlighted. JACQUES then assembled a team of dancers from the RWB Aspirant Program who were interested in being featured in the project. Two male and three female dancers were selected for the roles towards reflecting the gender diversity in the study. It was also desired that there be cultural diversity among the dancers to reflect the study population; however, it was only possible to recruit four dancers with mixed-European and one dancer with Japanese ancestry. [22]

4.2.2 Translating the five themes of young people's experiences living with anxiety through ballet and videography

MARKULA and DENISON (2000) ask "Why should we expect writing to move, embody or perform?" and states that "although our kinetic sense may not be used in the same way as language—to communicate—it does provide us with knowledge" (p.426). Translating the five themes representing the daily lives of young people with anxiety was the objective of the ballets that were choreographed by JACQUES. Through modern ballet, the dancers embodied the experiences of the co-researchers and depicted the themes through scenes that would become the vignettes, and when viewed in sequence would represent a day of a young person living with anxiety. JACQUES choreographed and directed the movements of the dancers, which were rehearsed in studio at the RWB School (Figure 2). The following quote represents JACQUES 's artistic vision behind the movements that he created for the vignettes.

"Artistically, the choreography was kept very pedestrian so as to connect with the site specific spaces instead of contrast with them. The choreography was also kept

3 This is the first KT activity from the Youth's Voices project. Additional strategies, including other arts-based (i.e., a photovoice exhibit) and more traditional KT strategies are planned for the dissemination of data.

pedestrian to connect more strongly with viewers through relatable movements. The emotion and the dancers were supposed to be seen as human, flawed, instead of ethereal and perfect" (JACQUES).



Figure 2: Studio rehearsals at the RWB School for *A Day in the Life of a Young Person with Anxiety* [23]

JACQUES knew the dancers through his work at the RWB School and spent a great deal of time working with them on the project so that they could embody the themes that they would be translating through their performances. JACQUES commented on how this process was meaningful for the dancers.

"It was very personal for all the artists involved. Everyone had a story, everyone knew someone who had lived through mental health issues. We are very thankful as artists that Dr. Woodgate took the leap of faith of putting academic research between our hands" (JACQUES). [24]

Once rehearsed, the dance pieces were then performed and recorded into video vignettes. The vignettes were produced and directed by WOOKEY. Scenes and soundscapes were developed by the WOOKEY and were refined iteratively through receiving feedback from core creative team to ensure the scenes remained true to the themes. Quotes from the interview transcripts were read as voice overs and once the video vignettes were completed the voice overs were translated from English into French and Cree, a North American Indigenous language (Figure 3). The following quote by WOOKEY speaks to some of the artistic choices that were made in the filming of the vignettes.

"When scouting locations for the video series, we wanted to make sure that the settings would show the feelings of anxiety that were described by the participants.

For example, in order to show how difficult it was to leave home in the morning, we chose an old home that had tall ceilings with thick wood moldings, and a hallway leading to the front door. We also used music and sound effects to try to give the audience an understanding of the feelings of our main characters. The research team had shared with us findings from the research study that certain noises were related to anxiety for many of the co-researchers and we wanted to highlight that. For example, to create a feeling of anxiety building up, we slowly built up the volume of the street noise—a noise that many co-researchers described as a source of their anxiety."



Figure 3: Stills from the video vignette series *A Day in the Life of a Young Person with Anxiety*⁴ [25]

4 Top-left: opening title for all vignettes; top-right vignette: *Hiding the Struggle* (performed by Isabella PISAPIA); middle-left vignette: *Fear of the Unknown* (performed by Yuya MIZUSHIMA); middle-right vignette: *Taking up Space* (performed by Victoria JENKINS); bottom-right vignette: *Feeling Different* (performed by Johan SCHROEDER); and, bottom-right vignette: *Can't You See I'm Struggling?* (performed by Kelsey MILLER). Available in English: <http://bit.ly/youthanxietystudy>; French: <http://bit.ly/youthanxietystudyfr>; and Cree: <http://bit.ly/youthanxietycree> [Date of access: September 9, 2017].

The vignettes were presented to the YAC for feedback and then presented at a release event at the Gas Station Arts Centre (community arts center in Winnipeg, Canada), which included a panel discussion with the core creative team, two of the dancers, and a member of the YAC. The event also included a small photo exhibit of some of the images that inspired the vignettes. Following the event, the videos were uploaded to an online platform (YouTube), were presented at numerous health conferences, and are being used in schools as teaching tools for units focusing on mental health and development. [26]

4.2.3 Challenges

Very few tensions arose during the creative process and the core creative team came away from the project feeling as though they had contributed to delivering an important message that reflected the findings of the study and the recommendations of the YAC. There were however some challenges in the development of the boundary object. The richness of the data generated from the research study meant that decisions had to be made on the themes that would be highlighted through this particular KT strategy. The creation of the YAC assisted in refining those themes that were to be highlighted; however, the research team also had to make decisions on which themes would be best suited to other future KT approaches. [27]

The decision to use dance, specifically ballet, as a means to convey the research findings was also an issue that the research team discussed. The research team recognized that using dance as a medium was not necessarily an arts-based KT approach that would resonate with all co-researchers, as well as with the general public. However, the research team, at the guidance of the YAC, was committed to using an alternative way of sharing research and to address this challenge, the research team in collaboration with the YAC is currently developing other KT products. [28]

There were also challenges in the development of the KT product that are reflective of participatory research. For instance, we would have preferred having a more iterative editing process that would involve several rounds of youth feedback and collaboration with the video production company. However, limitations in terms of budget and time commitments (of both the research team and co-researchers) meant that we had to limit rounds of editing. [29]

Finally, the research team has not yet been able to complete a formal evaluation of the KT product in creating the potential for enhanced empathy and understandings and reduced stigma for young people living with anxiety. However informal discussions with audiences and feedback received from co-researchers as well as from the public via social media have pointed to the power of the boundary object in helping to normalize the experiences of youth with anxiety and in addressing mental health related stigma. [30]

The commitment and passion of the various collaborators was essential to the success of the process of creating this boundary object. Specifically, the notion

that the production of the KT product must be driven by and reflect the voices of youth co-researchers—though their interview transcripts, photovoice images, and YAC recommendations—was the cornerstone of the project. The following quote by WOODGATE summarizes her thoughts on the overall success of the KT project, as well as its future uses.

"Arts-based knowledge translation strategies are extremely valuable for bringing people together to examine important and at times vexed questions relating to health and wellbeing. This project has been marvelous in its capacity to reach diverse audiences and holds great potential for further education on mental health and anxiety as it is experienced by young people." [31]

5. Discussion

The video vignettes that were collaboratively created are powerful boundary objects representing a day in the life of a young person living with anxiety. DURHAM-DeCASTRO and SHARP (2015) endorse artistic performance of research and state that it is "an innovative way to affect change in communities, offers exciting methodological innovations, and compels scholars to closely examine their disciplinary practices and ideologies" (p.412). Through arts-based representations it seems like the KT project team created the potential for enhanced empathy, responsive understandings of lived experiences, and the diminishment of stigma. Such translation of emotional knowledge historically has not always been easily accepted by academics and health practitioners, or as PARSONS' (2007) describes it: "Expressions of feelings were not thought to have truth value, having to do much more with sensitivity than with thought. In the simplest terms, they were more like exclamations (Ouch!) than like propositions (Doctor, my knee hurts)" (p.534). This lack of regard for "truth" within emotions is highly outdated, especially in the health field (CLEARY, 2011; WOODGATE et al., 2017c), and researchers and practitioners of health systems now recognize that understanding how people feel and experience their own realities is essential to advocating for and developing mental health services and interventions (DUNBERG, MÖLLER & SUNVISSON, 2016; STACEY & STICKLEY, 2010). [32]

The vignettes demonstrate the characteristics of effective boundary objects because they are meaningful translations of the themes of lived experiences and emotions for the co-researchers (SAPSED & SALTER, 2004), and they will be instrumental in conveying such experiences while maintaining their identity across multiple boundaries (CASH & MOSER, 2000; STAR & GRIESEMER, 1989). Art-viewing is especially effective as a "bridge" for socially isolated groups and can generate greater understanding around an issue through helping people make connections (LINESCH, 2004), destabilizing preconceived notions (LEE, 2007), and normalizing lived experiences (ROBERTS et al., 2011). Through sharing the vignettes in multiple venues, the knowledge built through the (R)CoP will be able to enter the worlds of people diverse viewers (i.e., educators, policy makers, service providers, families, and a wide general audience) who may have varying understandings of youth's experiences living with anxiety. As the vignettes take

on new life in these settings they will become boundary infrastructures (STAR, 2010), and potentially important frames for further discussion and collaboration. [33]

6. Conclusions

Anxiety is often poorly understood and minimized as something that is easily handled (CBC NEWS, 2016). Through the collaborative design of the boundary object WOODGATE and her research team aimed to promote understanding around the lived experiences youth struggling with anxiety. Since showing the videos through various platforms many people have reached out to us to express that the videos effectively depicted their suffering (or the suffering of a loved one), and that more work like this should be done. If health systems are to acknowledge the human rights of young people more work will need to be done towards understanding their lived realities from a variety of perspectives and within a diversity of contexts. [34]

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