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Abstract

This paper examines youth's disclosure experiences within the context of chronic illness, drawing on examples from IN•GAUGE, an on-going research program led by Dr. Roberta L. Woodgate. Youth's descriptions of their disclosure experiences provide valuable insights into the ways in which they use their voice in everyday life. This examination of the disclosure experiences of youth offers a lens through which the concept of youth voice in the research process can be understood and youth's agency foregrounded. We present implications for researchers, ethics boards, funding agencies, and others who engage in youth-centered research, and offer alternative terminology to use in characterizing the elicitation and dissemination of youth voice in the research process. We contend that conceptualizing such efforts as giving youth voice has the potential to discredit the significant agency and autonomy that youth demonstrate in sharing their stories, perspectives, and opinions within the research context. We advocate for the adoption of the phrase of providing or creating space for youth voice, as one alternative to the phrase giving youth voice

Keywords

arts based methods, photovoice, methods in qualitative inquiry, mixed methods, community based research

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Introduction

Adults who work with children and youth¹ have become increasingly concerned with the representation of youth voices in education, research, and policy. Spurred in part by the ratification of the United Nations Convention on the Rights of the Child (United Nations General Assembly, 1989), which includes in Article 12.1 the right for children to express their views on matters of concern to their own lives, researchers, practitioners, and policy makers in a wide range of fields have turned their attention to the inclusion of youth voices in a variety of projects and initiatives (Batsleer, 2011; Hadfield & Haw, 2001). Within the contemporary research environment, the concept of youth voice has become nearly synonymous with the active participation of youth in the research process (Hadfield & Haw, 2001; James, 2007). This includes the use of participatory methods of data collection as well as youth input on project scope, design, analysis, and dissemination. Such research has been characterized by many as a means of *giving voice* to youth (e.g., Gibson, 2019; James, 2007; Schäfer & Yarwood, 2008; Spyrou, 2011; Warming, 2005).

However well-intentioned, the use of such phrasing in describing the engagement of youth in the research process is problematic (Caron et al., 2017; Petronio et al., 1997). Conceptualizing research as *giving* youth voice negates their agency, characterizing them as in need of adult assistance in order to make their experiences validated and perspectives known. As James (2007) points out, by stating that children “need to be given a voice in research, the implication is that children are somehow disabled or prevented from speaking out, and that, therefore, they need a helping hand” (p. 262). Such framing positions youth as “reactive and disempowered,” waiting for “permission” from adults to use their voices (Petronio

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et al., 1997, p. 102). This contrasts with the principles and aims espoused by those who have adopted a youth-centered approach in their work, including the centering of youth agency and empowerment throughout the research process (Clark & Richards, 2017; Gallacher & Gallagher, 2008).

In actuality, youth have a voice; it is not something that can be given to them by adult researchers through participatory data collection and dissemination (Ajodhia, 2019; Petronio et al., 1997). Youth already possess and exercise their voices “with or without us, not through us or because of us” (Petronio et al., 1997, p. 102). Youth make many choices about how to use their voices in their daily lives, including who to talk to, what to say, and in what contexts to speak. In the sections that follow, we explore ways in which youth use their voice in the context of living with chronic illness, drawing on the literature regarding youth’s perspectives of the disclosure process as well as examples from IN•GAUGE[®], an on-going research program led by Dr. Roberta L. Woodgate. This examination of the disclosure experiences of youth offers a lens through which the concept of youth voice in the research process can be understood and youth’s agency foregrounded. We then present implications for researchers, ethics boards, funding agencies, and others who engage in youth-centered research, and offer alternative terminology to use in characterizing the elicitation and dissemination of youth voice in the research process.

Research Design

Data Collection

Through the research conducted under the IN•GAUGE[®] umbrella, Woodgate and her team have explored the experiences and perspectives of children and youth across a range of topics related to child and youth health and well-being, as well as the perspectives of parents and caregivers, service providers, and policy makers. The IN•GAUGE[®] research program strives to build equity and the legitimate inclusion of youth and their families in the research process, from the development of research funding applications, through data collection and analysis, and knowledge translation. Youth and other research participants in the various research studies provide direction as to their preferred depth of their desired engagement in the research process as an approach to increase their sense of emotional safety and autonomy.

All of the research conducted under IN•GAUGE[®] incorporate multiple research methods in order to gain a comprehensive understanding of each study’s research aims (Creswell & Creswell, 2017; Darbyshire et al., 2005; Teddlie & Tashakkori, 2009). Qualitative (i.e. open-ended semi-structured individual interviews, family interviews) and arts-based research methodologies (i.e. photovoice), and knowledge translation strategies (i.e. documentary films, dance productions, photo exhibits) were utilized in each of the research studies. Qualitative research methods have proven to be a powerful strategy for accessing youth’s conscious and unconscious feelings about difficult life situations (Woodgate et al., 2016, 2017). In each

research study, youth took part in an open-ended interviews. A *youth-as-expert* approach was adopted that recognized that young people are the experts in their own experiences. An interview guide was developed with open-ended questions that provided youth with an opportunity to focus on the most salient, and accessible aspects of their health and illness experiences. Field notes were also completed following each interview describing the interview context, salient themes, and any methodological challenges.

Following the first interview, youth were offered the opportunity to participate in the arts-based visual methodology of photovoice. Photovoice involves research participants taking photographs of their lives and their experiences, and then providing captions to those images as a means of documenting and reflecting on the issues significant to them (Wang & Burris, 1997; Woodgate et al., 2016). A number of scoping reviews focusing on the arts in qualitative research revealed that arts-based methods present unique opportunities for increased engagement of participants (Archibald et al., 2014; Boydell et al., 2012). Arts-based research methods can facilitate self-expression when an individual’s experience, feelings, and perceptions cannot be described by words alone (Fraser & Al Sayah, 2011).

At the end of the first interview, participants were provided with a digital camera and asked to take photographs over the next four weeks that depicted their thoughts and feelings about their health and/or illness experiences. Participants would then meet with the researcher to discuss the photographs taken in the context of a second interview. Photovoice was effective for a number of youth in these studies as an unobtrusive approach to gaining insight into their worlds (Strack et al., 2004; Woodgate et al., 2016). Participatory visual methods such as photovoice can assist in challenging the traditional power dynamic that may exist between the researcher and interviewee given that participants can selected what will be photographed and therefore discussed in the second interview setting (CohenMiller, 2017). The second interview used as a framework the SHOWeD framework which encourages the participant to share: What is Seen here; What is really Happening; How does this relate to Our lives; Why are things this way; How could this image Educate people; and What can I Do about it (Dahan et al., 2007).

Data Analysis

Data analysis occurred concurrently with data collection in all of the research studies as a means of allowing the research participants from each of the studies to have ongoing input into theme development, through the iterative research process and use of multiple interviews. Thematic data analysis occurred, identifying themes across participants and data courses, and delineating units of meaning. These units were then clustered to form thematic statements and themes extracted. Photographic images were formally linked to the corresponding text data, contributing to a more comprehensive understanding of youth’s health and illness experiences. For a number of these

research studies, a Youth Advisory Committee was formed that provided guidance on the themes selected by the research team, as well as how best to convey those themes using knowledge translation strategies.

In this discussion, we draw specifically on five studies that used qualitative and participatory arts-based methods in examining the experiences of youth living with anxiety disorders, bleeding disorders, human immunodeficiency virus (HIV), various chronic illnesses (e.g., arthritis, diabetes, Crohn's), and survivors of childhood brain tumors. Participants in these studies were at different stages in their journey with health and illness, including participants who were newly diagnosed to those who have been living with and managing their conditions for years. Although disclosure was not the focus of any of the IN•GAUGE® studies referred to here, many of the youth participants talked about the decisions they make regarding disclosure of their illness in describing their lived experiences, reflecting its importance in their daily lives. Drawing from these five studies as well as the existing literature, the centrality of voice in youth disclosure experiences is represented by four interrelated themes: deciding to use their voice, portraying the voice in social relationships, voices at odds, and work involved in using their voice.

Youth Disclosure Experiences

Disclosure refers to the sharing of personal information with others. In the context of youth chronic illness, disclosure can include sharing factual information about one's diagnosis (Gee et al., 2007), as well as information about one's ongoing health status (Hafetz & Miller, 2010). For youth living with chronic illness, disclosure is an ongoing process, the cumulative effect of which can be overwhelming (Siu et al., 2012). Decision-making related to disclosure has been characterized as both "complex and difficult" (Barned et al., 2016, p. 121), with youth facing many choices about who to disclose their chronic illness to, how to tell others about their illness, when to reveal this information, and what details to share.

Deciding to Use Their Voice

Youth who participated in IN•GAUGE® studies recognized that they have a voice and exercised their agency in daily life through the choices they make in navigating the world. Among youth in the research program, there was a sense that disclosure was an area of their healthcare management where they could take an increasing sense of ownership, in accordance with their evolving capacities. Disclosure was their story to tell. In describing disclosure as a personal decision, one young girl with a heart condition from the *Youth Involvement in Health Care Decisions* study expressed "cause it is kind of nice like keeping, if I want to keep my privacy I can just keep it a secret."

Although closely guarded, disclosure was discussed by many in a positive light. It was an active decision on the part of young people to reveal parts of themselves and was intricately tied to self-awareness and identity, and for many youth, it was also linked to a sense of pride. One young girl with



Figure 1. Bleeder pride.

hemophilia from the *Living with Hemophilia and other Bleeding Disorders* study shared a photograph of herself (see Figure 1) and explained:

I'm wearing the bleeder shirt. . . . Um I just wanted to get this shirt in because I'm proud . . . I talk about my bleeding disorder a lot just because it's so much part of my life. I'm very open about it. I'm proud that I've made it this far, like every year I turn a year older I'm impressed with myself that I've made it (chuckle). So this image is just kind of just pride, taking pride in what you can. . . . I just wanted to show people that I am courageous and that I am stronger than I think.

Consistent with prior research, the complex decision to disclose revolved in large part around considerations of practical needs (Hafetz & Miller, 2010; Kaushansky et al., 2017). Some youth wanted adults in a position of authority or peers to know about their health condition in order to appropriately respond in case of a medical emergency (Brouwer et al., 2012; Kaushansky et al., 2017). In other cases, youth required accommodations as a result of their health needs, such as accounting for frequent restroom breaks during class time, understanding of differing levels of ability and participation, or modified physical requirements in school and in the workplace (Kaushansky et al., 2017). Youth spoke of disclosure as a means to help ensure that someone had their back. The decision to disclose was also perceived by some youth as an indirect way of protecting their physical and mental self. One youth with rheumatoid arthritis from the *Youth Involvement in Health Care Decisions* study shared that the decision to disclose, despite being difficult, was at times necessary to encourage understanding:

- Participant:** I don't like telling my teachers cause they might feel bad for me or not believe me . . . but then I always get into trouble because I miss a lot of class and sometimes I should just tell them and get it over with than try and hide it.
- Interviewer:** What makes you like decide to tell or not to tell?
- Participant:** Um usually you hit the point where if you don't tell them they're probably not going to be as understanding or as helpful cause they'll just assume that you're skipping class, but I want to like I want to be there [in class] and I want to do all the things that regular people do.

In many cases, young people took on the role of advocates, using their voice to share and inform others of not only their experience, but about the condition in general (Brouwer et al., 2012; Yi & Nam, 2017). They felt that by being public and explaining their own illness to others, they were able to help foster public acceptance and awareness of the condition in general. Many participants in IN•GAUGE® studies had given presentations to their classmates or the public about their health conditions. Many also volunteered with community organizations dedicated to helping others in similar situations, or participated on youth advisory committees at hospitals or health-based community organizations to share their knowledge and experiences.

Another aspect of youth agency involved times where youth would employ their illness narrative in strategic ways. Participants shared anecdotes of times when they used their illness as a means to get out of activities that they were not particularly fond of, even though they were at that time capable of participating in that activity. One youth from the *Youth Involvement in Health Care Decisions* study who had a positive experience disclosing his Crohn's disease to friends shared that at times he declined invitations to social gatherings, telling friends that it was due to his Crohn's disease as opposed to having to explain that he just did not want to attend. Given that for many young people in the IN•GAUGE® research program chronic illness permeated their everyday lives, employing their illness narrative and using their voice in strategic ways was an attempt to regain some control. Telling selective truths at certain times was an exercise of youth agency in using their voice.

Portraying the Voice in Social Relationships

Disclosure is a dynamic and fluid process, embedded in complex social realities and in the practice of living with a health condition. Deciding whom to disclose to involves different lived relationships. Youth have reported disclosing their illness to family members and friends (Brouwer et al., 2012; Greene & Faulkner, 2002; Janin et al., 2018; Williams & Chapman, 2011), teachers (Boyd & MacMillan, 2005), and service providers (Gronholm et al., 2017). Older youth may also disclose to colleagues, employers, and current and former romantic partners (Gee et al., 2007; Greene & Faulkner, 2002; Janin et al., 2018; Kaushansky et al., 2017). For youth participating in IN•GAUGE® studies, it was not so much the role of the person in their lives that determined whom they would disclose to, but rather the level of trust in the relationship and their perceived reaction to and acceptance of the disclosure. Experienced or anticipated negative reactions from others, such as bullying, teasing, social exclusion, disbelief, and rejection, can make youth hesitant to disclose their chronic illness (Barned et al., 2016; Benson et al., 2015; Boyd & MacMillan, 2005; Brouwer et al., 2012; Coyne et al., 2019; Fair & Albright, 2012; Gronholm et al., 2017; Janin et al., 2018; Kaushansky et al., 2017; Protudjer et al., 2014; Williams & Chapman, 2011). Perhaps because of these negative reactions, some youth report only disclosing information about their

illness to those with whom they have established close, trusting relationships (Brouwer et al., 2012; Galano et al., 2017; Gronholm et al., 2017; Janin et al., 2018; Kaushansky et al., 2017; Protudjer et al., 2014). For example, one young man from the *Youth Living with Anxiety* study shared that he disclosed his anxiety in different ways and to different extents with his mother, grandmother, and friends. He disclosed the most to his friends about his experiences living with anxiety, while he shared less with his mom, stating only when he had anxiety, but not the reasons, out of fear for how she would react. On the other hand, he shared nothing at all with his grandmother, which was a source of tension since his grandmother believed that her role in his life should have determined his willingness to disclose.

Also important for youth in the IN•GAUGE® studies was how comfortable they were with other people knowing specific details about them, as well as how concerned they were in maintaining a certain level of privacy in their lives. Youth have reported "testing the waters" of their relationships by sharing hypothetical scenarios (Blake et al., 2012, p. 314; Fair & Albright, 2012) or limited amounts of information (Boyd & MacMillan, 2005; Fair & Albright, 2012) to see how their friends or romantic partners react, or by sharing untrue or irrelevant information to see if this information is passed on to others (Blake et al., 2012). Youth across IN•GAUGE® studies revealed that they tested the waters practicing who and how to disclose to, or only reveal so much at a time to gauge the other's response.

Youth's decision to disclose can be prompted by a desire for better understanding from those around them (Yi & Nam, 2017). Youth often choose to disclose to individuals whom they feel will be supportive (Boyd & MacMillan, 2005; Kaushansky et al., 2017), such as those who have shown interest in the youth's health (Kaushansky et al., 2017) or have had similar illness experiences (Gronholm et al., 2017; Janin et al., 2018). When a young person with ulcerative colitis from the *Youth Involvement in Health Care Decisions* study was asked what would influence his decision to disclose, he explained "If they are personal friends and if then if you are in the personal circle, you can know it. If you are not personal circle, then I would rather you did not know." Disclosure to trusted friends and family can provide youth with a sense of caring and support. Some of the young people in the IN•GAUGE® studies identified that when friends asked about their health in ways that prompted disclosure—initial or ongoing—it communicated a sense of caring and openness. People were also able to better give support to the young people, not only in emergency situations, but rather in youth's daily lives living with chronic illness, such as helping youth shield their disclosure in situations where they would prefer not to disclose, encouraging treatment adherence or coping strategies, and helping ensure youth's well-being. Another youth with diabetes from the *Youth Involvement in Health Care Decisions* study shared her positive experience of disclosure and how it prompted assistance from friends:

When my boyfriend and I were first dating, he had never met someone with diabetes so it took him a while to like notice my symptoms and everything . . . it was nice that he cared to learn more about it so that was helpful because sometimes I do need help like if my blood sugar is low he knows how much he's supposed to correct it . . . how much juice to give me.

The decision to disclose was shaped in large part by how young people wanted to be seen and what they wanted to reveal of themselves to others. The fear of being viewed or treated differently after others learn of their illness (Benson et al., 2015; Brouwer et al., 2012; Greene & Faulkner, 2002; Gronholm et al., 2017; Janin et al., 2018; Kaushansky et al., 2017) was also prominent among young people in the IN•GAUGE® studies. Many young people were keenly aware of their need or desire to “pass” as normal. One young person from the *Youth Involvement in Health Care Decisions* study shared:

I like to not talk about my arthritis very often with my friends because I try to be as normal as possible. . . . None of my friends really have the same thing so they can't really relate and I'd like to talk to guys more about sports [than] stuff [that] truthfully they don't really understand and I don't really need to talk about cause I get enough talking about it with uh doctors, parents and all that.

Although support was welcomed in some cases, it was possible for others to be too supportive. Some youth have indicated their concern about becoming the subject of others' sympathy or pity (Janin et al., 2018; Kaushansky et al., 2017). Participants expressed that such support, help, or sympathy could additionally mark them as different, and preferred it when those around them were understanding, but did not treat them differently from other teammates or classmates. Many of the young people in the study wanted to avoid their illness becoming a “big deal” even though at times their need for support conflicted with their desire to appear normal. Sometimes even supportive reactions could be experienced negatively if they were interfering, troublesome, or accompanied by unsolicited advice.

Voices at Odds

The IN•GAUGE® studies highlight that in the disclosure process, there are often competing voices about whose story it is to tell. Youth are often concerned that those who are aware of their condition, such as parents and other family members, may share that information with others without their knowledge or permission (Benson et al., 2015; Galano et al., 2017; Greene & Faulkner, 2002; Williams & Chapman, 2011). This can result in more people knowing about a youth's condition than the youth would like, particularly if they were diagnosed in early childhood (Boyd & MacMillan, 2005). Third party disclosure such as those made by family or friends without youth's permission was described as problematic. There were instances across the research program of parents sharing their child's diagnosis with others without their child's consent and unprompted by safety concerns. In so doing, the youth's health

condition was presented as someone else's story to tell. One young person from the *Youth Living with Anxiety* study who lived with anxiety and depression shared:

Sometimes I'll walk downstairs at mom's dinner party and I'm the subject of discussion and they'll talk about like me and how I have all these problems and I understand that she wants to talk and it's a good gossip topic but it's um it's kind of like a privacy thing, like it's not really any of their business and I feel that I should have the right who knows and who doesn't. . . . I just want her to respect that and to ask me before she tells people.

In another example from the *Youth Involvement in Health Care Decisions* study, a young person's parents disclosed health information to extended family members when asked not to. This resulted in a much greater restriction on how willing the young person was to discuss her condition and any other health issues with her parents, to the extent that she nearly did not discuss major surgery unrelated to her chronic health condition. In other instances, parents may discourage their children from disclosing their condition (Galano et al., 2017) even when the youth want to share their stories, highlighting that disclosure is a process often characterized by a negotiation of power dynamics.

The decision to disclose was also shaped by barriers that could work toward silencing youth voice. The amount of knowledge a young person has about their illness can impact their decision to engage in disclosure (Barned et al., 2016), as youth may anticipate difficulties in both their ability to explain their condition and in others' ability to understand this information (Benson et al., 2015; Kaushansky et al., 2017). A key barrier across the IN•GAUGE® studies involved situations where young people had ill health but were not yet given a diagnosis. Hence, young people struggled to adequately describe and be believed that they were in fact ill. A youth who had survived a childhood brain tumor from the *Survivors of Childhood Brain Tumours* study described how she had struggled with ill health for months prior to her diagnosis. Her immune system weakened and she experienced a number of flus. She then experienced migraines so bad that she had to walk with her head cocked to the side. She was diagnosed first with cluster headaches, and then premenstrual headaches. However, her family and teachers believed her symptoms were related to difficulties with school or peer relationships even though the youth repeatedly stated that this was not the case. The migraines continued, as did the development of new symptoms such as loss of appetite and sleep apnea however the youth had grown weary of sharing her symptoms to no avail. Six months later the youth was diagnosed with a brain tumor. In other situations, lacking adequate information about their condition that would allow them to promote their agency prevented disclosure. For example, one young person with HIV from the *Aboriginal Youth Living with HIV* study lacked understanding of what their diagnosis meant and asked the interviewer for more information. Accordingly, outside of the research setting, the participant could not be expected to disclose in a way that was empowering to them given that they did not know what their status meant.



Figure 2. Screenshot.

Barriers to disclosure also included not having the words to articulate their experiences. And yet even in these cases, youth demonstrated their agency by adopting different communication strategies, such as using someone else's words to share their experience. For example, one young person in the anxiety study submitted a photograph of a screenshot from a blog she followed that she would send to her mother on days when her anxiety was heightened (see Figure 2). The youth explained:

Um when I don't really know what to say to my mom but I'm having a bad mental health day, I just kind of send her pictures like these. . . . Uh it's just kind of like letting her know that I'm not really up for school and stuff. . . it's just 'cause I don't know I find it really hard to tell people my feelings.

Work Involved in Using Their Voice

The work of disclosure begins long before the act of disclosing and may include deciding what and how to tell a person, developing the narrative to be shared, and mentally rehearsing or imagining the disclosure. Youth have reported experiencing considerable anxiety and fear related to the disclosure process (Brouwer et al., 2012; Gee et al., 2007; Janin et al., 2018; Kaushansky et al., 2017), and emotions such as guilt, sadness, and embarrassment may strongly influence their decision to disclose (Galano et al., 2017; Gronholm et al., 2017). For youth in the IN•GAUGE® research program, disclosure involved a lot of mental and emotional work in not only making the decision to disclose, but also dealing with the work involved with the after-effects and any possible fall-out. Regarding always having to explain her allergies to people, one youth from the *Youth Involvement in Health Care Decisions* study stated, "I guess I just wish that I could just tell them I'm allergic and [they] say okay and be done." Growing weary from the repetitive and ongoing nature of disclosure was a theme reinforced by youth participants in all five of the IN•GAUGE® studies.

For many youth, deciding at what point in a relationship to disclose to others can also be a challenge (Coyne et al., 2019; Fair & Albright, 2012). The work involved in disclosure was not only about figuring out what to say and to whom, but also required that young people find the right time to share with others. One youth who had survived a childhood brain tumor from the *Survivors of Childhood Brain Tumours* study shared:



Figure 3. Visible symbols of illness.

And its funny 'cause when I, when I tell people sometimes that I had brain surgery, they're like uh why didn't you tell me sooner. . . and then, but then another thing I get all of the time is, why, why did you tell me so soon. . . or like, or like where did that come from like.

There were many situations where youth shared that having visible symbols of an illness helped to ease the work involved in sharing their story. These visible symbols may include splints (e.g., hemophilia), medical alert bracelets (e.g., diabetes) or head scarves (e.g., survivors of childhood brain tumors) (see Figure 3). While some youth preferred to conceal these visible symbols, for others, they could be helpful in providing an entry point for youth to share their story. One young teen shared that her medic alert bracelet invited conversation about her health condition. The teen from the *Living with Hemophilia and other Bleeding Disorders* study recalled that as a young child she felt uncomfortable by the unwarranted attention, but as she grew older and more knowledgeable about her diagnosis, she was more accepting of the curiosity of others, reinforcing that disclosure experiences and preferences can change over time:

When I was growing up like that's kind of the thing that like kids saw me saw, like they wouldn't just see me as "L," they would see me as you know the girl with the bleeding disorder kind of thing and I don't know people all the time ask me what I have the medic alert bracelet for, like people I don't know when I'm serving someone at the restaurant, they ask me that all the time. When I was younger I was kind of uncomfortable with it just because I felt different, but now it's, I'm fine with it, I've come to terms with it

Table 1. Implications of Youth Disclosure Experiences for Youth-Centered Research.

Disclosure Themes & Subthemes	Implications for Youth-Centered Research
Deciding to Use Their Voice	
Sense of ownership over disclosure process	Creating space for youth control in the research process through youth involvement in YACS, drafting calls for papers, ethics review boards, and reviewing grant proposals and publications
Disclosure to satisfy practical needs	Creating space for diverse motivations for research participation, including participation as a means of increasing other's understanding of lived experiences, the therapeutic nature of "sharing their story," advocacy, and strategic participation
Disclosure as a form of advocacy	
Strategic disclosure	
Portraying the Voice in Social Relationships	
Importance of trust	Creating space for relational elements of research process, including openness and curiosity, empathy and acceptance, receptive attention and deep listening, self-awareness and self-regulation, and nonjudgement and respect
Impact of others' negative reactions	
Desire for understanding & support from others	
Testing the waters	Creating space for youth to share their stories over time through repeated interviews, multiple methods of data collection, and allowing time and space within the research context
Controlling how one is seen	Creating space for youth to control the interpretation of their voices through involvement in data analysis and knowledge translation activities
Voices at Odds	
Competing voices	Creating space for valuing and respecting the voices of all participants (i.e., youth and parents), and attending to issues of importance to youth
Lack of knowledge of diagnosis as barrier to disclosure	Creating space for truly informed consent by providing youth with all information necessary to understand the research process and their place in it, in formats that facilitate comprehension
Not having the words to articulate their experiences	Creating space for non-verbal means of communication of lived experiences, such as the use of arts-based methods and new technologies
Work Involved in Using Their Voice	
Effort of disclosure & mental work	Creating space for recognition of the effort and mental work required in research participation and strategies to reduce participant burden
Finding the right time to disclose	Creating space for youth to determine right time to share their experiences through repeated interviews, multiple methods of data collection, and allowing time and space within the research context
Visible symbols of illness	Creating space for alternative means of communication of lived experiences that may decrease effort of participation

so... I have a better understanding of it now and um I know exactly what it is so... I mean I'm used to it [people asking questions] now but at the start it was kind of weird cause I thought it was like, it's none of your business but I don't mind telling people about it now... It kind of makes me unique and different from everyone else.

Implications of Youth Disclosure Experiences for Youth-Centered Research

As exemplified in the above discussion of youth disclosure experiences, youth exercise their agency and autonomy in deciding when, where, and how to share personal information on a regular basis. Youth engage in sophisticated and complicated decision-making in determining how to use their voice in relation to disclosure of illness, but also in many other aspects of their daily lives. For instance, none of the IN•GAUGE® studies described above were originally intended to focus on disclosure, with questions related to this phenomenon not

included in the interview guides or arts-based activity prompts. However, disclosure was a key part of the youth's illness experience, and therefore in retrospect, it was not surprising for youth to make it a key part of their story. Within the IN•GAUGE® research program, the interview space provided an environment for youth to assert or exercise their agency; in these instances, youth were directing the conversation. What youth shared with us about their experiences and their strategies for disclosure are also insights that we have adopted to mirror important aspects of their disclosure experiences within the research process (see Table 1).

Deciding to Use Their Voice

For youth with chronic illness, the decision whether to use their voice by disclosing their illness to others is an important component of their experiences. Similarly, the decision regarding if and how to use one's voice in the research process is a significant aspect of research participation. Central to youth's disclosure

experience was the importance of having a sense of ownership over the process. Within the research context, one way in which youth can be given greater control over the research process is through the involvement of youth as co-researchers (Alderson, 2001, 2008; Buck & Magee, 2017), which is sometimes accomplished through the use of youth advisory committees (YAC). YACs can play many roles in shaping the overall direction as well as the specific activities of a given project. Members of YACs can contribute their own knowledge and experience of the phenomena under study to help guide the development of a project's scope, provide input on the suitability of specific research methods to be used in a project, as well as offer feedback throughout the various stages of the project, including knowledge translation and dissemination (Woodgate et al., 2018). Additional strategies for affording youth greater control in project initiation and guidance include youth participation in drafting calls for papers/proposals, youth as members of institutional ethics review boards, and youth as reviewers of grant proposals and publications. The use of such strategies recognizes that the aims and objectives of adult-initiated projects may not be in line with those of youth, and creates an opportunity for youth input in key planning stages.

Other aspects of youth's decisions related to disclosure provide insight into youth's motivations for participating in research. As with disclosure of chronic illness, youth may have any number of reasons for participating in research, including practical reasons such as increasing others' understanding of their lived experiences, or the therapeutic nature of being able to share their story with others. When asked why she participated in the IN●GAUGE[®] health care decisions study, one youth stated:

Of myself and I'm proud of everything that I've been through and stuff. And it's kind of a privilege to be able to talk to you about it.

Other youth may view their participation in research as a form of advocacy, sharing their personal stories and experiences in the hopes of helping others with similar experiences. They recognize that participation in research may not bring immediate benefits to themselves but want to help others. As one young person who survived a childhood brain tumor from the *Survivors of Childhood Brain Tumours* study explained:

If I could share my story and someone, one person out of like a hundred, if one person can learn any bit of information from then like why not, like I just, I don't see any reason why you wouldn't want to, to help someone.

Youth may also perceive their participation in research more strategically, such as a stepping stone to more formal help seeking or in order to receive the benefits of participant compensation.

Portraying the Voice in Social Relationships

Youth described how their disclosure experiences were embedded within and influenced by the relationships they have

with others. A keen attention to the centrality of relationships within the research setting is similarly important for those engaging in youth-centered research (Leviton, 2019; Woodgate et al., 2017). Youth have described the importance of establishing trust in relationships prior to disclosure, the detrimental impact of others' negative reactions, and their desire for understanding and support from others. The conceptual framework of sustaining mindful presence in research with youth emphasizes these relational elements within the research encounter (Woodgate et al., 2017). Qualities integral to sustaining mindful presence include openness and curiosity, empathy and acceptance, receptive attention and deep listening, self-awareness and self-regulation, and nonjudgement and respect (Woodgate et al., 2017). Such an approach contributes to the researcher's ability to develop trust with research participants and to react appropriately to the information they share, thereby creating an environment in which youth may feel understood and supported in sharing their stories. Just as youth may test the waters with others by disclosing limited or irrelevant information related to their diagnosis, youth may initially be hesitant to share information with the researcher until this trusting relationship has been established. This emphasizes the importance of repeated interviews and multiple methods of data collection (Darbyshire et al., 2005; Murray et al., 2009; Read, 2018), as well as allowing for time and space within the interview context for youth's stories to be shared (Denov et al., 2019).

Another important element of disclosure described by youth was the ability to control how they were seen by others. Within the research context, youth can be given control over the ways in which their voices are interpreted within data analysis and shared via knowledge translation activities. For example, youth can be invited to analyze data collected in the projects in which they are involved, either individually or as a group (Best et al., 2017; Foster-Fishman et al., 2010). Researchers can also employ the method of member checking (Lincoln & Guba, 1985), providing youth the opportunity to review transcripts and/or preliminary analysis to ensure that the researchers' interpretations remain consistent with the youth's intentions. This also provides an opportunity for further clarification and elaboration (Greene & Hill, 2005; Thomas & O'Kane, 1998). Additionally, as part of the informed consent process, youth can be given choices in how their data will be shared after the study has ended, deciding if they want their images, artwork, or other products to be disseminated in addition to the stories they have verbally shared, and can choose their own pseudonyms to be used in knowledge translation products. Youth can also have control over the development of knowledge translation activities that allow their voices to be heard as they intended, and by the appropriate audience in the appropriate venues. Youth can assist in the development of knowledge translation products, author or co-author publications and presentations, and provide input on the manner in which these products will be shared (Buck & Magee, 2017; Foster-Fishman et al., 2010; Genuis et al., 2015). This may include scholarly publications as well as other formats and venues that allow for youth's messages to

be heard not just by researchers but also peers, families, practitioners, and other stakeholders. For example, some youth who participated in the IN•GAUGE® anxiety study suggested that their photos and stories be shared via an Instagram account created specifically for the project in order for the study findings to be shared more broadly.

Voices at Odds

Youth with chronic illness have emphasized their concerns related to competing voices in their disclosure experiences, a concern that may also be at play within the research context. This can be of particular concern for research that incorporates family member perspectives on youth experiences. Research that relies on parent perceptions of youth's experiences should be cautious about the conclusions they draw and the amount of personal information they share about youth. Such research should be explicitly framed as parents' perspectives and include a reflection that this may not be representative of their children's experiences. For research that incorporates both youth and family members, youth's stories should not be subject to verification or validation by adult family members (c.f. Shenton, 2010). Data collected from parents should be presented as complementary to that collected from youth, rather than attempting to reconcile any differences in the accounts they present or to present one story as the truth (Greene & Hill, 2005; Soffer & Ben-Arieh, 2014).

As in disclosure, power dynamics among family members and others in authority can be at play in youth's research participation. In addition to providing competing voices, parents and other authority figures may also prevent youth from using their voices altogether by withholding parental or institutional consent for youth's research participation (Heath et al., 2007; Skelton, 2008). Researchers should also be attuned to the power dynamics within the research encounter and take care that their own voices do not compete with those of youth. In addition to involving youth in the development of research aims and design, researchers should be open to listening to what is unexpected in the data (Thomson, 2008; Tilton, 2013), attending to the themes or narratives that emerge that may not have originally been the area of focus but are of clear importance to the youth. This involves paying attention to both what is said and what is unsaid, what is unexpected, and perhaps even undesired (Thomson, 2008; Tilton, 2013). This can take place within a single study or, as in the case of this discussion on disclosure, across multiple studies.

Some youth have expressed a lack of knowledge about their diagnoses as a barrier to disclosure, yet they knew intimately the feeling of ill health and how they felt. A lack of knowledge about the research process, its aims and objectives, researchers' expectations of youth as participants, and the ways in which their stories may be shared with others may similarly inhibit youth's ability to and comfort in participating in research. The informed consent/assent process is integral to ensuring youth are fully aware of their rights as research participants, as well as

the purpose of the research project and their role in it. Importantly, "the ability to give informed consent depends on the quality of the explanation" (Fargas-Malet et al., 2010, pp. 177–178). Researchers must ensure that youth are provided with an explanation of the research project that provides the necessary details to enable their full and informed consent/assent for participation. This consideration may go beyond that required by research ethics boards. For example, researchers should consider the reading levels of the consent forms required by research ethics boards (Skelton, 2008; Woodgate et al., 2016) and offer alternative, non-textual means of communicating the information contained therein (Fargas-Malet et al., 2010).

Just as youth may lack the words to articulate their experiences when engaging in disclosure, youth may also struggle to verbally share their lived experiences in the research context. The use of arts-based methods has long been viewed as an effective means of facilitating the expression of thoughts, feelings, and experiences that does not rely on participants' abilities to communicate with words (Leitch, 2008; Thomson, 2008; Woodgate et al., 2016). As one youth with anxiety from the *Youth Living with Anxiety* study who participated in photo-voice explained:

I mean for me in my pictures I've put um a mixture of like art and photography in one and I think it's really good 'cause photography is a form of art and art really it's supposed to express the way you feel at that moment . . . And I think it's just really good because sometimes you can't express everything in words.

New technologies can help to facilitate such arts-based approaches, leveraging participants' pre-existing social media presence to explore their daily life experiences (Volpe, 2019; Yi-Frazier et al., 2015) or introducing them to new media that facilitate the collection of visual and audio data (Beaupin et al., 2019; Hicks, 2019; Woodgate et al., 2014, 2016).

Work Involved in Using their Voice

Youth have described the effort and mental work involved in disclosure, and some may experience similar effort in the research setting. While many youth have described participating in research as a positive or even therapeutic experience, this may not be the case for all youth. Some young people may find talking about their life experiences to be stressful, while others may feel pressure in answering the interviewer's questions or completing assigned tasks. For example, after completing an ecomap (Rempel et al., 2007) during her interview, one youth with anxiety stated:

Like I don't know how long did it take me to do this map thing [ecomap] . . . Cause all the thinking involved and I was trying to focus on that, like you were like looking at me (chuckle) . . . and I'm just like am I taking too long . . . It's very nerve wracking, just like okay someone's breathing down my neck.

Finding the right time to disclose can be part of this mental work. As with the nature of youth voice as embedded in social relationships, this highlights the importance of allowing time for youth to share their stories through the use of repeated interviews, multiple methods, and affording adequate space and time within the research encounter for youth's stories to emerge. It also emphasizes the importance of employing strategies to reduce the potential for participant burden, including providing appropriate participant compensation and being flexible in scheduling the time and place for interviews (Newington & Metcalfe, 2014), and selecting research methods that may help to facilitate participant communication of their lived experiences (Hill, 2006). For example, just as splints, medical alert bracelets, and other visible symbols of illness may alleviate some of the work involved in disclosure, arts-based methods for youth in the IN•GAUGE® studies helped reduce the effort involved in trying to find the words to say to share their experiences. For other youth, however, such methods actually increased the work of participation, and prompted some youth to feel that they had to create something profound and artistic. Researchers should anticipate differences in participant preferences and offer alternative methods of data collection (Hill, 2006).

Conclusion: Creating Space for Youth Voice

Youth's descriptions of their disclosure experiences within the context of chronic illness provide valuable insights into the ways in which they use their voice in everyday life. These insights highlight how youth make decisions about when and how to use their voice in disclosing their illness, the ways in which the disclosure process is embedded within the relationships they have with significant people in their lives, the challenges and power dynamics they face in choosing to use their voice, and the effort involved in so doing. These insights offer important parallels for disclosure within the context of youth-centered research. Central to these insights is youth's agency and autonomy in using their voice in matters of importance to them.

Accordingly, we encourage scholars, practitioners, and others who work with youth to consider carefully the words they use in describing the processes in which they strive to elicit, incorporate, and disseminate the voices of youth in their work. As noted previously, conceptualizing such efforts as *giving* youth voice has the potential to discredit the significant agency and autonomy that youth demonstrate in sharing their stories, perspectives, and opinions within the research context. As one alternative to the phrase *giving* youth voice, we advocate for the adoption of the phrase of *providing* or *creating space* for youth voice, as suggested previously in our own work and that of others (e.g., Denov et al., 2019; Levitan, 2019; Petronio et al., 1997; Woodgate et al., 2017). Such wording recognizes that as the adults facilitating the work, we are not granting youth the ability to speak, but rather are striving to create a space in which their voices are welcomed, respected, and heard.

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Notes

1. Throughout this paper, we use terms such as “children,” “youth,” and “young people” interchangeably.

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