

A Narrative Review of Ethical Issues in Participatory Research with Young People

YOUNG
28(4) 363–386, 2020
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DOI: 10.1177/1103308819886470
journals.sagepub.com/home/you



Olivia Cullen¹ and Christine A. Walsh¹

Abstract

Youth participatory action research (YPAR) is a methodology to engage youth in the research process and is focused on emancipation and empowerment. Although benefits have been outlined, ethical issues have also arisen. This article provides a narrative review of peer-reviewed literature regarding these ethical issues. After applying standardized search criteria and inclusion/exclusion criteria, 26 articles remained. Examination of the literature revealed seven categories of ethical issues: level of participation, power, consent, risk/benefit ratio, confidentiality and anonymity, remuneration and empowerment. To mitigate these issues, recommendations are provided, including: being explicit about, and inclusive of, youths' participation; critically reflect upon the researcher as 'expert'; consent as an ongoing process and based on capacity rather than biological age; balancing the need to protect youth with the benefits of participation; challenge blanket anonymity policies to maximize participation and empowerment; remuneration beyond monetary compensation; and incorporate concepts of empowerment into research design and process.

Keywords

Participatory research methods, youth participatory action research, youth, young people, ethics, ethical issues, literature review

Participatory action research (PAR) is a research methodology with a focus on emancipatory ideologies and engages directly with communities as co-researchers to create knowledge and social action beneficial to those living in the communities (Kidd & Kral, 2005; McTaggart, 1991). PAR seeks change at larger sociocultural or structural levels as well as at the individual level, while explicitly challenging

¹ Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada.

Corresponding author:

Olivia Cullen, Faculty of Social Work, Mackimmie Tower 301, 2500 University Drive NW, Calgary, AB T2N 1N4, Canada.

E-mail: Olivia.cullen@ucalgary.ca

traditional power dynamics between researchers and participants (Cornwall & Jewkes, 1995). PAR is used as a research method to address issues of social injustice and marginalization (Cahill, Quijada Cerecer, & Bradley, 2010). Youth participatory action research (YPAR) is a form of PAR with an explicit focus on youth involvement in the research process. Researchers have also identified the role of YPAR in supporting capacity building and critical thinking skills of young people (Cahill et al., 2010; Ozer, 2017). By virtue of their age as well as their developmental stage, young people have been identified as a marginalized group (Graham & Fitzgerald, 2010). Specifically, young people are often considered inherently vulnerable by institutional review boards (IRBs) who are granting ethics approval for research projects (Yanar, Fazli, Rahman, & Farthing, 2016). It is important, however, to recognize that young people experience marginalization and vulnerability very differently based on other identity markers such as race, gender, class and ability (Arnett, 2014; Prout, 2011).

In research involving youth, participation limits are often set primarily based on strict age categories, typically in alignment with the age of majority where the research is taking place (Chabot, Shoveller, Spencer, & Johnson, 2012). Because of these limits, youths' voices are not always included in policies and practices that impact their lives (Campbell & Trotter, 2007), generally being viewed as passive research participants, rather than as actively engaging with the research process (Graham & Fitzgerald, 2010). However, over the past three decades, young people's participation in research has garnered increasing interest. The resultant calls for young people to be active in matters impacting them has led to an increasing trend to move towards research with, as opposed to on, youth. At the same time, traditional ethical frameworks, and specifically IRBs can be restricting and limiting in the opportunities available to actively include young people (Graham & Fitzgerald, 2010).

Within academic literature, the notion and extent of young people's participation in research has been understood and integrated to varying degrees. Further, conclusions have been mixed as to the benefits and drawbacks of utilizing YPAR, and in how to address ethical issues that may arise. In recent years, three reviews of YPAR literature have focused on these issues. Jacquez, Vaughn, and Wagner (2013) examine the extent of youth participation and reviews by Anyon, Bender, Kennedy, and Dechants (2018) and Shamrova and Cummings (2017) summarize the outcomes of YPAR studies. To our knowledge, there are no published reviews relating specifically to ethical dilemmas in YPAR, which presents an important gap in the knowledge-base. This literature review seeks to answer the question: what are the ethical issues that arise when doing participatory research with youth? Thus, the purpose of this article is to review literature that addresses ethical issues in YPAR and to synthesize this discussion, particularly in relation to the (potentially) heightened ethical concerns present in participatory research. This narrative review is organized into four sections. First, the literature review methods are described. Second, the results of the literature review are shared, with details regarding the included articles. Third, the review discusses the seven ethical issues present within literature, including (a) level of participation; (b) equalizing power; (c) consent; (d) risk/benefit ratio; (e) confidentiality and anonymity; (f) remuneration; and (g) empowerment, respect and ownership. Finally, this article concludes with recommendations arising from these seven ethical issues.

Methods

A narrative review is a type of literature review that ‘provides a comprehensive narrative syntheses of previously published information’ (Green, Johnson, & Adams, 2006, p. 103). Narrative reviews differ from other literature reviews in that the research question and focus is usually broader (Collins & Fauser, 2005; Green et al., 2006). While narrative reviews have been critiqued for not being as rigorous as systematic reviews, narrative reviews can be more useful in providing comprehensive coverage of a topic (Collins & Fauser, 2005). A narrative review can draw conclusions on a topic with different and broad perspectives and provide up to date knowledge about a specific topic (Ali, 2018; Green et al., 2006). Given that discussions on YPAR have drawn various conclusions about its usefulness as a research approach, the extent to which young people are actually involved in YPAR projects, and how to manage ethical issues that may arise, a narrative review can help to summarize and describe these debates (Green et al., 2006).

To enhance the methodological rigour of this narrative review and provide a fuller picture of literature, a systematic search strategy was utilized in the following databases: PsycInfo; CINAHL Plus with Full Text; Social Work Abstracts; Family and Society Studies Worldwide; Family Studies Abstracts; SocINDEX with Full Text; ERIC; and PubMed. The search terms used were: PAR (and variations including: YPAR; action research; participatory research) and ethics (and variations including: ethical issues; ethical considerations; ethical dilemmas; ethical challenges; ethical problems; ethical standards; ethical principles) and youth (and variations including: adolescent; young adult; teen; child; student; school aged). The search was limited to peer-reviewed articles written in English and published between January 2000 and June 2018. Criteria for inclusion were that the article focused on participatory research with an examination of ethical issues. Articles were excluded if the population focus was adults, or exclusively young children (under the age of 15). Articles that included young people across childhood, adolescence and emerging adulthood were included. In this review, youth refers to adolescence (ages 15–17) and emerging adulthood (18–25) based on criteria outlined by Arnett (2014).

The initial search resulted in 1,415 articles with four other articles identified through hand-searching of reference lists; once duplicates were removed, and abstracts searched for relevancy, 124 articles remained. The articles were retrieved for full-text review and articles were included if they had a focus on ethical issues within participatory research and the population of the article was youth between the ages of 15 and 25. After this criteria was applied 26 articles remained, which comprised the sample included in this review (see Figure 1).

Results

There are 26 articles included in this review, the details of which are presented in Table 1. Most articles are from the United Kingdom ($n=13$), four are from Canada, two from the United States, two from Ireland, one from Australia, two from United Kingdom researchers with research in various locations throughout Africa, one article is from Colombia and one is from Malaysia.

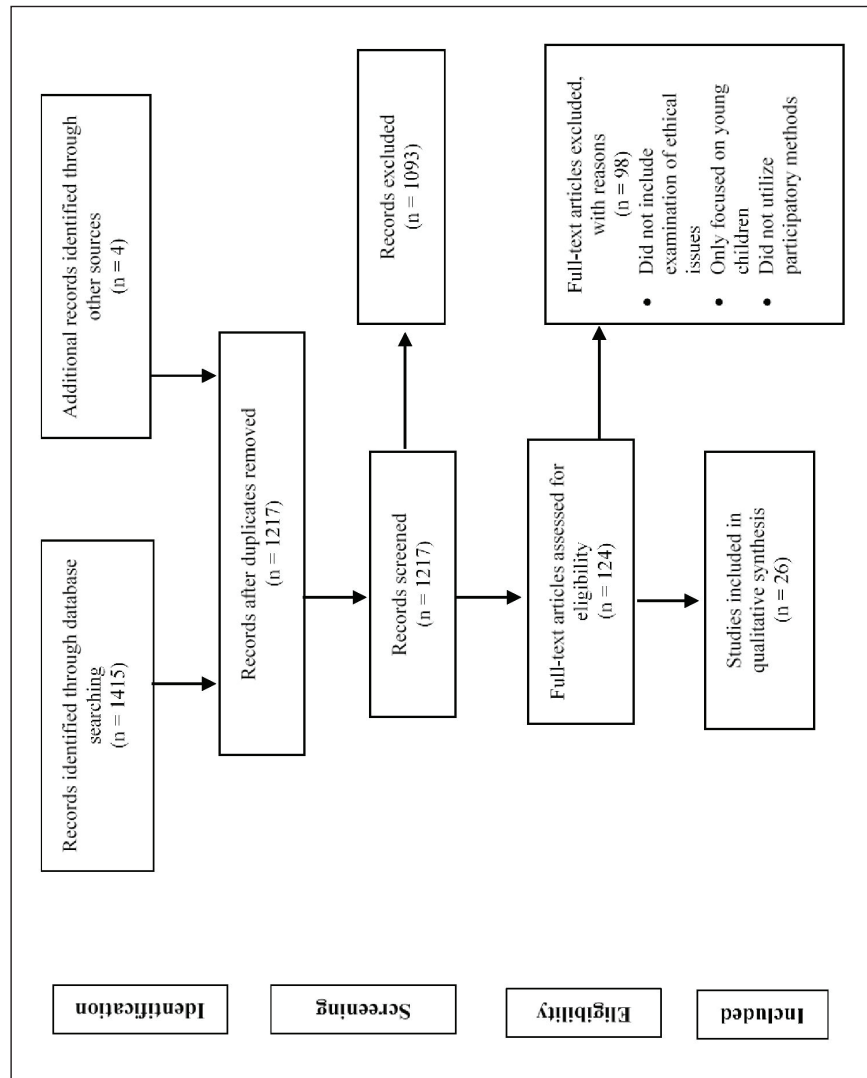


Figure 1.

Source: Adapted from Moher, Liberati, Tetzlaff, & Altman (2009).

Table 1. Characteristics of Articles Included

Reference	Country	Theoretical Orientation	Research Question/Purpose	Population n(Age)	Methodology
Balakrishnan and Cornforth (2013)	Malaysia	Rights-based, specifically UNCRC ¹	Can moral education (a mandatory subject in Malaysia) be more relevant to youths' everyday lives	22 (16–17)	Participant observation; focus group; interviews; journals; audio/video recording
Bradbury-Jones and Taylor (2015)	UK	Rights-based, specifically UNCRC	Critiques young people's participation in research.	N/A	Literature review
Campbell and Trotter (2007)	UK	Rights based	Explore invisibility of youth who are not involved in traditional aspects of society (e.g., work, school)	6 (17–21)	Action-empowerment approach (only made it to planning stage)
Chabot, Shoveller, Spencer, and Johnson (2012)	Canada	Constructivist epistemology	Examines challenges in conducting YPAR ² with multiple stakeholders (e.g., ethics boards, school boards).	4 (19–22) youth as co-researchers; N = unknown (16–24) as interview participants	Interviews
Coad (2012)	UK	Rights based, specifically UNCRC	Reflects on practical approaches to involving young people as co-researchers	102 (13–17)	Photo elicitation
Cooper (2005)	Kenya/ UK	Rights-based, specifically UNCRC	Investigates the situation of an out-of-school population in the Dadaab refugee camp	11 (17–25)	Interviews; focus groups
Fargas-Malet, McSherry, Larkin, and Robinson (2010)	UK	Rights-based, specifically UNCRC	Reviews methodological, practical and ethical considerations in YPAR	N/A	Literature review
Gombert, Douglas, McArdle, and Carlisle (2016)	Scotland (UK)	Unknown	Reflection on the ethical dilemmas of YPAR with formerly homeless young people	N = unknown (16–25)	Observation; interviews; photovoice
Graham and Fitzgerald (2010)	Australia	Rights-based, specifically UNCRC	Reviews evidence and discusses critical issues in YPAR	N/A	Literature review

(Table 1 Continued)

(Table 1 Continued)

Reference	Country	Theoretical Orientation	Research Question/Purpose	Population n(Age)	Methodology
Holland, Renold, Ross, and Hillman (2010)	UK	Rights-based, specifically UNCRC	Critically examines process, challenges and opportunities of YPAR with youth in care	8 (10–20)	Ethnography; interviews; groups; diaries; scrapbooks; digital media
Hooper and Gunn (2014)	UK	Rights-based, specifically UNCRC	Reflections on the process of service providers collaborating with young people to determine what support, services and care children in care will receive	8 (unspecified age) in YPWG ³ 35 (8–19) participated in consultation with YPWG	Interviews; writing/journaling
Horgan (2017)	Ireland	Rights-based, specifically UNCRC	Explores youth advisory groups as a means of empowerment; reflects on more participatory methods in light of ethics requirements	93 (7–17)	Focus groups; youth advisory group
Houghton (2015)	Scotland (UK)	Feminist/rights based	Outlines participatory ethical approach that promotes inclusion and empowerment of young people in research and policy about domestic violence	8 (15–19)	Interviews; focus groups; film-making; direct engagement with politicians
Kennan, Fives, and Canavan (2012)	Ireland	Rights-based, specifically UNCRC	Explores ethical and methodological challenges of YPAR with hard to reach population	26 (5–17)	Interviews
Khanlou and Peter (2005)	Canada	Unknown	Examines IRB ⁴ review in YPAR	N = unknown (avg. age 17)	Focus groups; Interviews
Kia-Keating, Santacrose, and Liu (2017)	United States	Unknown	Illuminates community's view and impact of health problems related to violence, acculturative stress, discrimination and disparities.	22 (high school aged)	Photovoice

Lac and Fine (2018)	United States	Unknown	Explores researchers' interest and challenges in doing YPAR.	I 1 (not specified – Freshman)	Observations; interviews; survey
Liegghio, Nelson, and Evans (2010)	Canada	Sociology of childhood	Examines the use of YPAR with children having mental health concerns	N/A	Literature review
Lushey and Munro (2015)	UK	unknown	Explores YPAR with young people leaving care in two studies, including the ethical, practical and data quality issues	N = unknown (18–25)	Surveys; interviews
Petrie, Fiorelli, and O'Donnell (2006)	UK	Rights-based, specifically UNCRC	Explores YPAR on the topic of young pregnancy. Is it possible beyond tokenistic involvement and is it beneficial?	N = unknown (16–20)	Interviews; focus groups; youth advisory groups
Porter (2016)	Ghana, Malawi, South Africa/UK	Unknown	Reflects on three case studies (two involving young people as co-researchers). Discusses ethical concerns, rewards and complexities of YPAR with marginalized groups	Study 1: N = unknown (9–18) Study 2: N = unknown (9–25)	Interviews; surveys
Ritterbusch (2012)	Colombia	Care ethics	Argues for ethics practice to bridge disconnect between IRB and YPAR. Offers ways to operationalize and expand IRB guidelines	N = unknown (not specified) female street youth	No description of specific methods
Smith, Monaghan, and Broad (2002)	UK	Unknown	Can YPAR work? Will the results be accepted as legitimate? Should we undertake YPAR? Is it worth the additional demands on time, resources and expertise?	> 100 (not specified)	Focus groups; interviews; observation
Tucker (2013)	UK	Rights-based, specifically UNCRC	Considers challenges, ethical dimensions of YPAR in abuse/neglect research.	102 (17–25); 8 young people for co-inquiry group to analyse data	Interviews; focus groups

(Table 1 Continued)

(Table 1 Continued)

Reference	Country	Theoretical Orientation	Research Question/Purpose	Population n(Age)	Methodology
Walsh, Hewson, Shier, and Morales (2008)	Canada	Social determinants of built environment	Identifies ethical dilemmas that developed during a PAR project to promote community development through improving leadership capacity of youth	11 (13–17)	Photovoice; art exhibit; pre/post surveys; reflective journaling; interviews
Yanar, Fazli, Rahman, and Farthing (2016)	UK	Rights-based, briefly UNCRC; sociology of childhood	Explores the shift towards YPAR and the tensions with methods and ethics boards	12 (12–18)	Focus groups; interviews; surveys

Source: The Author.

Notes:

¹ United Nations Convention on the Rights of the Child.

² Youth Participatory Action Research.

³ Young People's Working Group.

⁴ Institutional Review Board.

n is the number of participants.

Support for the inclusion of youth and the various ethical considerations can vary depending on the national context. For instance, many countries believe it is a young person's right to participate in research and use the United Nation Convention on the Rights of the Child (UNCRC) to support this belief. However, not all countries (e.g., the United States) have ratified this convention and so may differ in supporting youth inclusion in research. Further, though young people may be able to legally consent for themselves, this may not always be culturally appropriate. In Malaysia, for example, parental consent was gained even for participants over 18 (Balakrishnan & Cornforth, 2013). Cross-cultural or cross-national research can also compound potential ethical considerations. For example, Balakrishnan and Cornforth (2013) discuss some of the challenges specific to the cultural and political context in Malaysia 'where strict state control is used to form a cohesive multicultural society' (p. 583). Cooper (2005) also identifies the extra considerations needed in working across nations and cultures in her research with young people in a refugee camp in Kenya. She adds that within a refugee camp, it is especially important to pay close attention to power as research can become exploitative when people living within the camps are reliant on foreign agencies for resources. Researchers note extra barriers related to language differences as well as extra considerations about power between the researcher and participants (Balakrishnan & Cornforth, 2013; Cooper, 2005). It is essential to consider the national and cultural contexts of participatory research with youth. In the articles presented, ages of participants ranged from five to 25. The earliest publication date is 2002 with the majority of the articles ($n = 20$) being published in or after 2010. Data collection methods utilized in the studies include qualitative interviews and focus groups, photovoice, surveys, ethnography, participant observation and arts-based approaches. It is important to note that including studies with varying methods has the potential to impact the quality of the review and reduces the ability to make direct comparisons between various studies. However, because the focus of this review is the ethical dilemmas that arise within YPAR rather than *how* researchers enact YPAR, the specific data collection methods are not central to this review.

Examination of this literature reveals seven broad categories of ethical issues, including: (a) level of participation; (b) equalizing power; (c) consent; (d) risk/benefit ratio; (e) confidentiality and anonymity; (f) remuneration; and (g) empowerment, respect and ownership, each of which are discussed in-depth in the discussion section. See Table 2 for a description of ethical issues present within included articles.

Discussion

Ethical Issues

Level of participation: While all articles in this review address youth participation, the extent of participation differs. On one hand, in their participatory research with hard to reach populations, Kennan, Fives, and Canavan (2012) term young people as 'research subjects', including them merely as qualitative interview participants. This level of involvement is markedly different from the majority of studies in this review. Some studies utilize youth advisory groups (YAGs) to provide input and recommendations for the research (Hooper & Gunn, 2014; Horgan, 2017; Petrie, Fiorelli, &

Table 2. Ethical Issues Present in Articles

Reference	Equalizing Power	Consent	Risk/Benefit Ratio	Ethical Issue(s)		
				Confidentiality/Anonymity	Remuneration	Empowerment, Respect, Ownership
Balakrishnan and Cornforth (2013)	X	X	X			
Bradbury-Jones and Taylor (2015)	X		X	X	X	
Campbell and Trotter (2007)		X			X	
Chabot, Shoveller, Spencer, and Johnson (2012)	X		X	X		
Coad (2012)	X			X		
Cooper (2005)	X					X
Fargas-Malet, McSherry, Larkin, and Robinson (2010)		X		X		
Gombert, Douglas, McArdle, and Carlisle (2016)	X			X	X	
Graham and Fitzgerald (2010)		X	X			
Holland, Renold, Ross, and Hillman (2010)	X			X		
Hooper and Gunn (2014)	X	X				
Horgan (2017)	X	X	X			X
Houghton (2015)	X	X	X			X
Kennan, Fives, and Canavan (2012)		X	X	X		
Khanlou and Peter (2005)	X	X	X			
Kia-Keating, Santacrose, and Liu (2017)	X	X				
Lac and Fine (2018)	X					
Liegghio, Nelson, and Evans (2010)	X		X	X		X
Lushey and Munro (2015)	X			X		X

Petrie, Fiorelli, and O'Donnell (2006)	X	X	X	X	X
Porter (2016)	X	X	X	X	
Ritterbusch (2012)	X	X	X	X	
Smith, Monaghan, and Broad (2002)	X				X
Tucker (2013)	X		X		X
Walsh, Hewson, Shier, and Morales (2008)	X	X		X	X
Yanar, Fazli, Rahman, and Farthing (2016)	X			X	X

Source: The Author.

Note: Level of participation is not included in this table as all articles address youth participation to some extent.

O'Donnell, 2006), though level of participation in YAGs also differs. For example, decision-making power remains with youth in Hooper and Gunn's (2014) YAG; notably, the YAG, rather than adult researchers, was able to make decisions about how funds were spent. Horgan (2017) created a YAG to mitigate potential barriers to youths' 'deep participation' (p. 251) as a consequence of the timelines required within the government-funded research. She notes that the YAG, which was established immediately after the study was approved, had a key role in the research from that point on until after data analysis. In contrast to the two previous examples, youth in the YAG in Petrie et al.'s (2006) study have little decision-making power and are primarily utilized for consultation and advice. Across the participation spectrum, eight studies in this review include young people as co-researchers involved in data collection, specifically interviewing and data analysis (Chabot et al., 2012; Coad, 2012; Cooper, 2005; Hooper & Gunn, 2014; Lushey & Munro, 2015; Porter, 2016; Smith, Monaghan, & Broad, 2002; Tucker, 2013). At the broadest level of participation, three studies involve young people in all aspects of the research project including research question development, data collection, analysis and dissemination (Cooper, 2005; Houghton, 2015; Kia-Keating, Santacrose, & Liu, 2017). By including young people in the data analysis phase, researchers note that the analysis is not only deeper and more nuanced than it would have been otherwise, but it also has language and terminology chosen by youths, rather than imposed by adult researchers (Cooper, 2005; Lushey & Munro, 2015). In this vein, Cooper (2005) notes that the interpretations were more holistic, and youth were able to make novel political, economic and social connections.

However, it is important to listen to young people, and not force participation on youth. For example, some youth in Houghton's (2015) research did not want to be part of the analysis phase as they considered it to be a 'boring endeavor' (p. 239). Thus, while it is generally recommended that youth should be included meaningfully in as many aspects of the research project as is feasible, youth should be consulted with and listened to with regards to their level of participation and researchers should follow youth cues in determining when and how they will participate.

Equalizing power: Equalizing power is frequently identified as a priority in YPAR and overcoming power differentials is central in the discussion of ethical issues (Bradbury-Jones & Taylor, 2015). Coad (2012) notes that while relations of power are evident in most research, this is more prominent in research with young people. There are 22 articles in this review that address equalizing power in some form. Coad (2012), for example, advocates for open and ongoing dialogue with young people; whereas Houghton (2015) advances equal participation of youth and adults to mitigate power as exemplified by the young researchers in the study co-developing an ethical process throughout the research. Similarly, Liegghio, Nelson, and Evans (2010) indicate that sharing of power between young people and adults is of utmost importance; this, they argue, does not mean adults and youth are the same, but rather it acknowledges that young people have things to offer within the research relationship. As another example of equalizing power, Holland et al. (2010) indicate that they purposefully left the research question broad to leave space for young researchers to make choices about the research focus. Hooper and Gunn (2014) further this discussion by noting that while they gave input to the young people's working group when asked, youth had autonomy over decision making.

Researchers in this review discuss including youth in positions of power to avoid accusations of tokenism. Lushey and Munro (2015), however, indicate that involving youth in all aspects of the research just to avoid tokenism should not be done at the 'expense of conduct[ing]...robust research employing traditional methods' (p. 534). In their research, Petrie et al. (2006) discuss developing a local YAG to include young people in power positions. However, the national advisory group made the recommendation that all decision-making responsibility remain with the adult researchers and the YAG be only for advice and consultation. This demonstrates how adults in positions of authority (the national advisory group, in this case) can dictate roles within the research and reinforce power differences. While Petrie et al. (2006) recognize and attempt to rectify the problems associated with tokenistic participation of youth in research, they do not consider the influence of the national advisory group in reinforcing the tokenistic participation of youth.

Holland et al. (2010) argue that power is relational and can be repressive or empowering depending on context. PAR researchers, they suggest, tend to describe power and agency as something that adult researchers can give to young participants. For example, adult researchers placing youth in certain positions to equalize power, rather than allowing young people to decide on their own roles. Rather than mitigating power differences solely through giving young people more, Tucker (2013) advises that adult researchers need to adopt a self-reflexive and critical stance towards their 'presumed expertise, knowledge and understanding' (p. 274).

Articles in this review illustrate that power imbalances or hierarchies exist not only between adults and young people, but also among youth through peer networks, or subcultures (Bradbury-Jones & Taylor, 2015; Holland et al., 2010; Horgan, 2017). Holland et al. (2010) acknowledge that navigating power imbalances between adult and youth researchers is relatively easy as young people have significantly more knowledge in many aspects of the research; however, ensuring equitable participation between youth is still necessary. Further, Walsh, Hewson, Shier, and Morales (2008) note that some young people are more comfortable with different research aspects, like addressing the media. This will impact whose voices are heard, and as such, the authors identify concerns about the potential to cause or reinforce power imbalances among youth (Walsh et al., 2008).

Language is another way in which power differentials can be either perpetuated or mitigated. For example, Hooper and Gunn (2014) recommend using young people's own language to allow youth to feel ownership, emphasize the importance of their participation, and highlight the significance of their conclusions. On the other hand, some researchers may not recognize the way language can be used to further power imbalances. For instance, while Coad (2012) advocates for equalizing power and the use of multiple participatory tools to engage young people, she consistently uses a variation of this phrase: 'young co-researchers in *my* [emphasis added] project' (p. 14), indicating that while young people are involved, the ownership of the project remains with the researcher.

Consent: Consent, a necessary and fundamental component of research, is particularly critical in research including youth. Authors in this review discuss that research with young people typically requires the cooperation and the consent of other parties (Fargas-Malet, McSherry, Larkin, & Robinson, 2010), since youth are often not deemed competent, or as lacking the maturity necessary to provide consent

(Fargas-Malet et al., 2010; Graham & Fitzgerald, 2010). However, as Graham and Fitzgerald (2010) argue this understanding 'invites presumption that [youth] are at risk and vulnerable to exploitation in the research process and therefore in need of protection' (p. 141). Two main themes emerging from the review articles regarding consent are informed and ongoing consent, and the role of adults as gatekeepers to research participation.

Gaining consent for research is vital, requiring assurance that participants have a good grasp on the realities of participation. Fargas-Malet et al. (2010) point out that the quality of the explanation of the research directly impacts the ability of participants to provide informed consent. Thus, the onus is on the research team to ensure that the explanation given to youth participants is easily understood, and that questions are encouraged and answered. Further, Fargas-Malet et al. (2010) encourage adult researchers to review materials with, and get feedback from, youth participants.

As YPAR projects aim to include youth as equal participants, the consent process may be muddled as researchers move away from a protectionist viewpoint to working as cooperative partners (Balakrishnan & Cornforth, 2013; Khanlou & Peter, 2005). While most articles in the review refer to consent, eight articles specifically contend that the consent process needs to be iterative and ongoing with researchers being continuously reflexive and checking in with participants' understanding frequently (Balakrishnan & Cornforth, 2013; Fargas-Malet et al., 2010; Gombert, Douglas, McArdle, & Carlisle, 2016; Houghton, 2015; Kia-Keating et al., 2017; Khanlou & Peter, 2005; Petrie et al., 2006; Ritterbusch, 2012). In this vein, it is important that the youth participants understand not only the research project but also the nature of ongoing consent; consent and decisions about involvement needs to be an ongoing process rather than a one-time agreement at the beginning of a study (Petrie et al., 2006; Ritterbusch, 2012).

Within multicultural settings, consent can be further complicated. Indeed, researchers and participants may not speak the same language, share the same culture or have similar understandings of the consent process. Cultural differences may require increased flexibility, room for differences and ongoing negotiation so as not to be seen solely as fulfilling a check-list for legitimizing the research (Balakrishnan & Cornforth, 2013). In instances of multicultural research, Balakrishnan and Cornforth (2013) claim that respect and trust are particularly important to increase the likelihood of reflexivity and ongoing informed consent. Khanlou and Peter (2005) indicate that since YPAR typically involves groups or communities, group consent may override individual consent, with individuals feeling pressure to participate. In this regard, it is imperative that researchers understand the implications and role of community in the consent process (Khanlou & Peter, 2005). Porter (2016) further outlines difficulties with informed consent in global contexts; specifically, Porter (2016) questions how researchers can ensure informed consent for young co-researchers or participants when data is used and stored in different countries than the research is taking place.

The idea that youth are inherently vulnerable has been identified as leading IRBs, researchers and parents to act as gatekeepers, controlling the participation of youth and thereby, making it difficult for young people to actively or meaningfully engage in research (Bradbury-Jones & Taylor, 2015; Fargas-Malet et al., 2010; Graham & Fitzgerald, 2010; Horgan, 2017; Kennan et al., 2012). Consent requirements,

particularly in Western societies, are based on chronological age typically in line with the age of majority (Chabot et al., 2012). Thus, for youth under the age of majority, parents/guardians are required to give consent, while youth provide assent—a process whereby young people give passive agreement. A youth's assent can then be overruled if parental consent is refused (Chabot et al., 2012). In the case where youth require parental consent to participate in research, parents become gatekeepers to participation. When research involves marginalized or at-risk youth, the need for parental consent often creates barriers to their participation (Campbell & Trotter, 2007; Hooper, 2014; Kennan et al., 2012). For instance, Kennan et al. (2012) describe difficulties in acquiring parental consent as their study focuses on young people with caretaking roles, generally because of parental inability. Further, Chabot et al. (2012) note that requiring parental consent for sensitive topics such as sexual health for sexual minority youth, could increase young people's risk if their caregivers do not know, or do not support their sexual orientation. Ritterbusch (2012) builds on this discussion indicating that in her research with street girls in Colombia, many of whom had previously been sexually exploited by their parents, parental consent to mitigate risk is counterintuitive.

Parents/guardians are not the only gatekeepers to young peoples' participation. When research is being conducted in schools and supported by school-based authorities, youth may feel obligated to engage in research (Fargas-Malet et al., 2010). In addition, when gatekeepers, such as teachers, social workers or community workers support recruitment, they may put forth particular young people who they deem as more 'appropriate'. This, whether intentional or not, can be a tool to control the process and outcomes of the research (Horgan, 2017; Kennan et al., 2012). Kennan et al. (2012) also note that service providers as gatekeepers can further increase power inequalities as young people may feel obligated to participate out of fear of losing support from service providers. Ultimately, judgements must be made by researchers, parents/guardians and IRBs about whether consent is sought from youth, parents/guardians, or both (Bradbury-Jones & Taylor, 2015; Graham & Fitzgerald, 2010).

Researchers note the complexities of gaining consent from youth or gatekeepers, and some note the importance of young people negotiating consent for themselves. Houghton's (2015) study of domestic abuse policy puts youth participation and consent at the fore. The researcher challenges age as a key factor in consent/assent processes, which gives young people the ability to provide consent, regardless of age. The youth in this study all have experiences of domestic abuse and for them, having control over their consent to participate is essential (Houghton, 2015). However, young people in the study also recognize the need to negotiate consent with their mothers, who have also been victimized, and so they utilize ground rules especially for things like media appearances that may 'out' their participation (Houghton, 2015). Consent and assent, although negotiated differently in various projects, are important ethical issues identified in YPAR literature.

Risk/benefit ratio: Protection of young people remains at the forefront of the risk and benefit discussions of involving youth in participatory research. As Bradbury-Jones and Taylor (2015) reinforce, 'the protection of children is always paramount, whatever the cost' (p. 170). However, articles throughout this review challenge and expand on this protectionist view to discuss who decides what is risky or not, at what point intervention is necessary to protect youth from risk, and the ways that this may

vary according to the research setting (Balakrishnan & Cornforth, 2013; Chabot et al., 2012; Houghton, 2015; Liegghio et al., 2010; Ritterbusch, 2012; Tucker, 2013).

There tends to be a general understanding within social research that 'good research is research that results in social benefits' (Balakrishnan & Cornforth, 2013, p. 586). As YPAR focuses on challenging dominant discourses and questioning the status quo, it adheres to the directive of social benefits (Balakrishnan & Cornforth, 2013; Khanlou & Peter, 2005). Ritterbusch (2012) furthers this idea by indicating that in contexts where lives may be at risk, protection is a social and political action not merely 'an abstract ethical standpoint underpinning written guidelines' (p. 17). Building on this, Balakrishnan and Cornforth (2013) discuss that in repressive countries participation can be dangerous and individuals may need protection. Houghton's (2015) YPAR research with young people exposed to domestic violence is another example of challenging risks. Youth in this study are involved in all aspects of the research in order to fully integrate their voices. Houghton (2015) concludes that while distress may be inevitable, youth say they can manage or minimize this, and the possibility of risk should not be grounds to not participate. Further, Liegghio et al. (2010) discuss potential risk and repercussions for youth when research includes critiques of systems they are part of, for instance the mental health or educational system. However, Liegghio et al. (2010) also note that for young people with mental health issues, involvement can be particularly beneficial as a means of empowerment and supporting social inclusion.

Tucker (2013) indicates the need to value the rights of participants while considering the best interests and potential harms to youth who with experiences of abuse and neglect. Because of the emotional difficulty inherent in this research, Tucker (2013) describes frequently questioning if this research is in the best interests of the young people, noting that being transparent with youth and providing options like speaking with trained counsellors, serves to address some concerns. Ultimately, Tucker (2013) concludes that it is the decision of the young people to decide whether involvement is harmful. Youth in both Houghton (2015) and Tucker's (2013) studies discuss the importance of being able to make their own choices about participation. Particularly in Houghton's (2015) study, young people note participation as beneficial when social change was possible.

Confidentiality and anonymity: When working with youth, confidentiality is a key ethical issue, both as a means to protect youth and as a way to ensure that they feel comfortable participating in the research. Petrie et al. (2006) advocate for transparency in the consent process to certify that young people understand the limits of, and are engaged in ongoing discussions about, confidentiality. While researchers aim for confidentiality as best they can, there are limits, especially if young people disclose illegalities, or when parents/guardians request access to information (Fargas-Malet et al., 2012). Further, as noted previously, when parental consent is required young people's ability to confidentially participate in research can be impeded (Chabot et al., 2012).

Smith et al. (2002) claim that certain research methods, PAR in particular, pose greater risks to confidentiality. Other authors concur that this may be exacerbated when young researchers and participants are in the same social groups (Bradbury-Jones & Taylor, 2015; Smith et al., 2002). For instance, Holland et al. (2010) note confidentiality as a particular concern arising with respect to engaging young people in data analysis. As some participants may choose to share stories only with a

researcher and not the whole team, data analysis decisions are impacted and can influence the conclusions and connections made with the data (Holland et al., 2010). In contrast, Coad (2012) discusses providing co-researchers with training on confidentiality and anonymity, and creating ground rules when analysing the data so that young people remain involved in analysis.

Along with confidentiality, anonymity has been cited as an ethical issue within, and essential to, youth participatory research. In some instances, anonymity has been critiqued as it can hamper the ability of young people to take credit for their work. Gombert et al. (2016) indicate the potential issues with required anonymity, though they do not problematize or advocate against blanket anonymity. On the other hand, young people in Yanar et al.'s (2016) research question how to claim their work and effect change if they are not able to be acknowledged by name. In this case, Yanar et al. (2016) note the exception to anonymity for authorship purposes only, resulting in young researchers getting credit for their work as named authors on publications. Walsh et al. (2008) note that in their study, confidentiality and anonymity, in parts of the research, cannot be guaranteed. Rather, youth participation is considered public as the research involves an exhibit of participant's artwork at the community level. The researchers further suggest that ethical issues arise when anonymity requirements are different for participants within the research, based on parental consent. This, the authors advance can lead to inequalities in power, voice and ownership of the research (Walsh et al., 2008).

Remuneration: Remuneration is contentious within research discussions, particularly in low-income countries or for marginalized groups (Bradbury-Jones & Taylor, 2105). Bradbury-Jones and Taylor (2015) conclude that regardless of the mode of payment, young people must be compensated for their involvement and contribution to research and 'to do otherwise would exacerbate power inequalities between adult and child researchers' (p. 168). Smith et al. (2002) similarly note remuneration, including transportation and childcare costs for the young parents in their study, as a requirement to acknowledge and value them. Monetary payment is not always possible within research studies, nonetheless Gombert et al. (2016) state that researchers need to create opportunities as a means of remuneration for participants, including: public speaking and presenting, building their resumes, and other worthwhile activities as negotiated with participants. This, however, becomes increasingly difficult when IRBs or parents require anonymity of young people.

Many authors conclude that some form of payment to youth participants is essential to valuing their contribution and to ensure that they do not feel that they are being taking advantage of (Bradbury-Jones & Taylor, 2015; Gombert et al., 2016; Smith et al., 2002). On the other hand, in their study of young people, marginalized by their lack of involvement in employment, education or training, Campbell and Trotter (2007) caution that the payment and training of young people as co-researchers 'began to feel exploitative rather than empowering' (p. 37), leading the authors to question if seeking out disengaged youth to research their 'invisibility' is of benefit them, or further exploits their marginalization.

Empowerment, respect and ownership: The goal of empowerment is one of the most cited reasons for adopting a YPAR approach particularly to highlight the issues or concerns of previously marginalized populations (Cooper, 2005). Empowerment is identified in multiple articles within this review, indicating its centrality in YPAR.

For example, in Houghton's (2015) study, empowerment for youth with experiences of abuse is noted as one of three necessary components for young people's participation in research. Also, youth in the study articulate that they should not be involved if change, such as the ability to promote their own rights and participation in national policy making, is not possible (Houghton, 2015).

Petrie et al. (2006) and Yanar et al. (2016) involve young people in authoring published papers as a form of ownership over the research. Part of the research by Walsh et al. (2008) includes an exhibit to display artwork, photographs and reflections the young people created. Such a display can give young people ownership and a sense of empowerment over their work. Walsh et al. (2008) note that their community project garnered much media attention with youth being involved in radio, television and newspaper interviews. In this example, youth report feeling valued for the work their work. However, media outlets portrayal of these youth as at-risk, could be further stigmatizing (Walsh et al., 2008). In contrast, youth in Petrie et al.'s (2006) study report negative experiences with media, as they were not supportive of the young people.

Within the context of a refugee camp, which Cooper (2005) describes as 'a unique site of disempowerment' (p. 474), YPAR can be particularly useful as youth researchers can integrate their experiences fully to include political, economic, social and cultural aspects, thus providing a rich and comprehensive portrayal. Further, other outcomes of participation include employment activities for some refugee youth, and additional resource commitments from major non-governmental organizations (Cooper, 2005). Cooper (2005), however, cautions that the positive benefits resulting from the project do not mean it is 'enough to counter the structural challenges inherent to life as a young refugee in a camp' (p. 474). Although PAR, in this situation, allows the voices of refugee youth to be heard, helping to empower them and further their opportunities, there is minimal impact on the complex structural issues facing the refugee community. Thus, it is important to remember that the values of YPAR, such as empowerment and social inclusion, do not automatically accrue to youth participants and must be actively incorporated through all phases of the research (Houghton, 2015).

Recommendations and Conclusion

Participatory inclusion of youth in research is a relatively recent endeavour. As articles in this review highlight, young people's rights are paramount in participatory approaches, not just as a consequence of the expertise they have about their lives, but also ground the research in the importance of having the perspective and opinions of youth recognized and reflected (Bradbury-Jones & Taylor, 2015; Fargas-Malet et al., 2010). This review adds to the important and growing literature on youth participation in research. Importantly, this review highlights essential ethical issues that may arise when conducting YPAR as well as the various ways researchers have addressed these concerns. The conclusions of this review agree with Bradbury-Jones and Taylor's (2015) assertion that there is mounting evidence to show that young people are able to take ownership and participate actively in the research process when treated as competent and given decision-making power. Finally, this review provides recommendations for each of the seven ethical issues that have been presented in this article.

Recommendation 1: Level of Participation

Youth participation varies significantly between different research projects. While some researchers qualify any youth involvement in research as participatory, most researchers acknowledge that research is not participatory unless youth go beyond the status of ‘participant’ and are involved in multiple aspects of the research. Researchers employ various strategies to include youth in the research process, a common strategy being the use of YAGs (YAGs; Hooper & Gunn, 2014; Horgan, 2017; Petrie et al., 2006). In consulting with young people, other researchers found that they may not want to be involved in all aspects of the research (Houghton, 2015). Thus, while it is generally recommended that youth should be included in as many aspects of the research project as is feasible, youth should be consulted and listened to with regards to their participation. Utilizing Hart’s (1992) Ladder of Youth Participation can support researchers to critically evaluate the extent of youth participation and when aspiring to participatory approaches, it is recommended that researchers be explicit about the nature of youths’ participation.

Recommendation 2: Equalizing Power

Power relations and equalizing power within the research process is a significant ethical consideration within this body of literature. Given the emancipatory nature of PAR approaches (McTaggart, 1991) and the explicit call to challenge power dynamics (Cornwall & Jewkes, 1995; Kidd & Kral, 2005), it is no surprise that equalizing power takes primacy in these debates. While frequently examined, the degree to which researchers attempt to address power inequities is varied. Further, the degree to which power inequities are addressed can be seen in the decision-making power, and ownership young people have within research endeavours. It is recommended that researchers critically reflect upon the notion of researcher as expert, while actively engaging in equalizing power throughout the research process. It is important to not deny power imbalances exist, but rather be open about these dynamics while working to actively challenge them.

Recommendation 3: Consent

The consent process in YPAR has been extensively discussed. Basing consent on biological age alone can be problematic in YPAR given the emphasis on participation; young people should be understood as co-researchers and fully engaged in the process. Further, having parents/guardians, other adults, and IRBs as gatekeepers has led to concerns that this will inhibit the participation of many youth. While acknowledging it is not always possible to have youth provide consent, it is recommended that this process be iterative and ongoing, with informed consent based on capacity and not only biological age, to ensure young people are aware of the research project and their rights within it (Balakrishnan & Cornforth, 2013; Chabot et al., 2012; Gombert et al., 2016; Houghton, 2015).

Recommendation 4: Risk/Benefit Ratio

Understanding and balancing the risks and benefits of participating is important for YPAR. While researchers agree that risks should be avoided, and young people protected within research processes, there are varying understandings about how this is to be enacted. Within some of the studies in this review, young people themselves identified that though potential risks exist, it was worth engaging in research and risk can be mitigated within the process (Houghton, 2015; Tucker, 2013). Finally, authors in this review highlight the need to consider different cultural contexts in which risk is present (Balakrishnan & Cornforth, 2013; Ritterbusch, 2012). Thus, it is recommended that in future participatory youth research, researchers need to be mindful in balancing the primacy of youth participation with protection, take context into account and involve youth in these discussions.

Recommendation 5: Confidentiality and Anonymity

Confidentiality and anonymity are central to any research discussion. In YPAR, due to the nature of young people being co-researchers, and often times interviewing their peers, confidentiality and anonymity are critical ethical considerations (Chabot et al., 2012; Smith et al., 2002). However, when viewing YPAR through an emancipatory and empowerment lens, the requirements of anonymity may be challenged. At times, youth themselves desire to be acknowledged and have ownership over their contribution to research (Yanar et al., 2016). While exceptions have been made to anonymity requirements, it is infrequent and remains challenging (Petrie et al., 2006; Yanar et al., 2016). From this, comes a recommendation for increased flexibility, particularly within IRBs, and challenging blanket anonymity in order to maximize participation, empowerment and acknowledgement of young people within research.

Recommendation 6: Remuneration

The ethical issue of remuneration is one of the more contested dilemmas within YPAR research. While some authors argue that young people must be paid or compensated in some way for their involvement (Bradbury-Jones & Taylor, 2015; Gombert et al., 2016), others expressed that paying people to participate because of their marginalized status can be exploitative (Campbell & Trotter, 2007). In light of this, it is important for researchers to critically think about remuneration. Beyond monetary compensation, it is recommended that researchers identify other forms of remuneration and, in particular, pay attention to the possibility of increased risk or coercion related to remuneration for marginalized populations.

Recommendation 7: Empowerment

Finally, empowerment is a commonly addressed ethical issue within this review and is noted as a main objective and outcome of YPAR (Ozer, 2016, 2017). Empowerment is linked to young people's perceived control over their lives, their critical thinking and decision-making capacities and their motivation to engage with their

communities (Ozer, 2016). Results from this review highlight that youth participation is both viable and an important means of empowerment for youth and it is recommended that concepts of empowerment be thoughtfully incorporated into the research design and practices.

This review underscores the importance of including young people as active and authentic participants in research. Both a rights-based approach and the sociology of childhood perspectives align with YPAR principles and support YPAR as a meaningful approach to equalizing power hierarchies, challenging social exclusion and supporting young people as leaders in challenging systems of oppression to enhance their lives and communities (Ozer, 2016, 2017). However, Bradbury-Jones and Taylor (2015) point out that ‘participatory methods do not straightforwardly equate to freedom’ (p. 168) nor to empowerment and social inclusion. As findings from this review reinforce, these benefits are accrued through reflexive processes involving both adult and youth researchers. With YPAR, and indeed all research methodologies, certain ethical issues need to be considered. Importantly, as this review suggests, there are ways to minimize such concerns and create a research environment conducive to authentic youth participation. Ultimately, for YPAR to be successful and YPAR principles to be enacted, researchers must remain critical and reflexive, while acknowledging the knowledge and expertise that young people possess.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The authors received no financial support for the research, authorship and/or publication of this article.

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Authors' Bio-sketch

Olivia Cullen is a Doctoral student in the Faculty of Social Work at the University of Calgary and has a Master's degree in social work with a clinical specialization. Her research focuses generally on youth, with a specific focus on youth transitioning to adulthood and youth who have experienced sexual abuse and exploitation.

Christine A. Walsh is a Professor and Associate Dean (Research and Partnerships) Faculty of Social Work, University of Calgary. Her research is concerned with enhancing well-being and promoting social justice for marginalized populations including vulnerable youth (Indigenous and racialized youth and youth with histories of child abuse, poverty and homeless or conflict with the law).