Process and reflection on participatory action research with young carers in a community context

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Abstract
This paper outlines my experience as a participant with the Young Carers Project, a participatory action research (PAR) study through the University of Waterloo’s Murray Alzheimer Research and Education Program (MAREP). This article will describe my successes and challenges during this process, and discuss future applications of PAR for health promotion activities involving young carers.

Keywords: youth engagement; participatory action research; young carers; adult allies; identification; support; upstream health promotion; social determinants of health
Introduction

Canadian governments and communities have been slow to direct attention towards young carers, a term that defines youth and young adults who are impacted by their provision of care for a family member and/or close friend (Aldridge & Becker, 1999; Charles, Stainton, Marshall, 2012). This is problematic because young carers who are not supported are at risk for negative caregiver outcomes that have far reaching developmental, social, and health implications in later life (Charles, Marshall, Stainton, 2010; Bleakney, 2014). Raising awareness about young carers can be difficult, as they are often described in the literature as a hidden or silenced population (Charles, 2011; Ali et al., 2013; Stamatopoulos, 2015). In response to the emerging Canadian research highlighting the rising prevalence of young carers, the gap in legislative support, and the hidden nature of young carers, the province of Ontario has emerged as a hub of young carer initiatives (Baago, 2005). The Young Carers Project (YCP) of Waterloo Region represents one such initiative.

The YCP took steps to identify gaps in support for young carers in the Waterloo Region and made the decision to employ a participatory action research (PAR) approach. PAR approaches have been used effectively to partner with youth on health promotion interventions in a variety of contexts (Boutilier et al., 1997; Harper & Carver, 1999; Mason & Boutilier, 1996; Poland et al., 2002). Through focus groups with young carers, community members and researchers, the YCP was able to identify and explore impacts unique to the young carer experience.
I was a young carer recruited for this project and in time, in line with the core tenets of PAR, my role shifted from that of participant to researcher, fostering my confidence and ability in conducting research. The praxis inherent in PAR empowered young carers involved in this project to contribute to the knowledge translation of the study findings into accessible young carer resources: namely, a documentary, guidebook, and a website. This paper will outline two main points: 1) how the YCP used a PAR approach to create space for critical and collective inquiry, reflection, and action among young carers, researchers, and community members, and 2) describe the YCP’s effectiveness as a health promotion initiative directed at building young carer supports in the Waterloo Region.

**Background**

In 2009 the YCP of Waterloo Region was formed by a small group of alumni from “Leadership Waterloo Region” in partnership with Murray Alzheimer Research and Education Program (MAREP). The issue of young carer support and awareness became especially pressing after data from 2012 Statistics Canada census revealed that there were 1.25 million caregivers aged 15–24 who provided some form of care to a family member or friend with a long-term health condition, disability, or aging needs (Battams, 2013). Though the incidence of young carers in Canada is quite high and expected to rise (Stamatopoulos, 2015), there were only three dedicated young carer programs in Canada at the time. This provided the impetus for the YCP in Waterloo Region.
An initial environmental scan was conducted to determine the extent to which local social service agencies in the Waterloo Region supported young carers in the community and identify gaps in services. This scan revealed that most agencies did not formally acknowledge and/or support young carers in their scope of practice. The paucity of legislation and supports for young carers meant there was little public awareness of their existence, and the lack of research focused on Canadian young carers remained a significant barrier.

As a result the YCP decided to support young carers through a research project. Each member of the YCP research team brought a unique skill set to the research component of the project, and represented different facets of the Waterloo Region community. The goals of the research project were to identify the needs of young carers in the community, to create resources based on the young carer experience to best meet their needs, and to use these resources to help community organizations understand how they can better support young carers. A member of the larger project’s working group, whose background included community/participatory based research experience, steered the YCP to a PAR approach.

**Making it PAR**

Participatory action research is rooted in critical approaches to social science research (Denzin & Lincoln, 1994). This research strategy acknowledges the power that academic researchers have in regards to knowledge generation and access to systems of knowledge. Participatory research attempts to subvert this normative construction by
decentralizing knowledge production and equalizing the power between researcher and subject. This reflects the understanding that participants have legitimate knowledge and can contribute to knowledge creation to answer relevant problems that stem from within the community (Lind, 2008). This process is thought to facilitate participant enlightenment and enhance capability (Denzin & Lincoln, 1994; Greenwood et al., 1993; Lind, 2008).

The degree of participation achieved and the amount of action generated in PAR is mediated by a host of complexities, and thus varies project to project. Regardless, utilizing a PAR framework was a conscious decision made by the community collaborative of the YCP of Waterloo Region. As a participant within this framework, there were several tenets of the PAR approach that shaped my personal successes and challenges.

Successes and Challenges

Diversity in Research

Collaboration between those in the “researcher” role and those in the role of “participant” was evident throughout the project. This project did not feel like traditionally structured research; rather, a space was created in which researchers and participants worked together for the advancement of a common goal. Researchers were co-participants and participants were co-researchers. I appreciated this aspect of the
project in part because, at the age of 21, I wanted more opportunities to develop my skills in research, but especially because of my diversity in relation to the researchers.

All of the research team members were white, adult women. As a second-generation Canadian of Ethiopian/Eritrean background, I was self-aware of my contrast as a black male. Considering that I am a member of a marginalized minority group and the history of institutional racism within the academic industrial complex (Smith, 2007; Savan et al., 2009), I am often wary of potential systemic power imbalances at play in community research projects. Thankfully, in light of this homogeneity, the research team often acknowledged their privilege and my voice never felt muted or diminished in focus groups. I attribute this to the researchers’ intention to use the PAR approach to subvert underlying power imbalances. I would also like to note that the researchers were a very caring and socially conscious group of individuals who supported me every step of the way during this project, and continue to support me to this day.

Situated Knowledge

Members of the research team had dedicated time to review academic literature focused on the young carer population. However, it was the knowledge of the experience communicated by participants like myself that was privileged throughout the project. This was an important feature for me, as my start in the project was marked with self-doubt and insecurity; I was not entirely convinced I met the criteria to be a young carer. Even despite the years in a supporting role for my family, I did not intuitively consider my lived-experience as one worthy for the research project. The lack
of self-identification was a common theme among other young carers in our focus groups, and this was also reflected in the young carer literature. Because my voice was prioritized within this PAR framework, I had the opportunity to personally process what it meant to be a young carer on equal ground with researchers.

The research team was also unique in its ability to blend the insider/outsider perspective with two of the four members personally identifying with the young carer experience. One member grew up in a family dealing with her sister’s chronic genetic illness, and had previously been involved with Sib’s associations. The other member grew up in a family dealing with her mother’s acute bipolar disorder. The PAR approach created a positive space to bridge the experience of current young carers with adults who retrospectively considered their experiences as young carers, shedding light on the pervasiveness of the young carer role and the far reaching impacts it has on development and identity affirmation.

Emergence and Fluidity
The project was also marked by an emergent process – the focus and methods were guided by dynamic communication among the research team and young carers, and largely remained in a fluid state. The research component of the YCP was conducted during the 2012/2013 school year (September to June), and the research team committed to facilitating one meeting with participants each month. Kitchener City Hall, Kitchener, Ontario, was selected as an appropriate location for such meetings as it was easily accessible by public transit and was convenient for booking evening meeting
space. Though the initial trajectory of the project timeline appeared straightforward on paper, the recruitment and attrition rate of young carers in the project proved to be a difficult and ongoing challenge. The reality was that research involving youth, and especially young carers who by their nature are a hidden population, needed to be flexible. Thankfully, the PAR method and preliminary research enabled the forward movement of the project.

In addition to recruitment materials distributed in the community, members of the research team also recruited participants from within their existing networks. This was how I was recruited, which was key because I would not have been involved were it not for one specific adult ally who recognized my caregiver role and supported me every step of the way. This positive relationship, as well as the relationships fostered within the larger group, was strengthened by the flexible and transparent nature of the project. There was not a lot of pressure to attend focus groups, meetings were rescheduled to fit young carers’ agendas and busy lives, and there was always an offer for transportation in case someone needed it and refreshments were always provided. The success of the YCP in the face of the recruitment challenges reflects the importance of adult allies when empowering youth in both PAR and health promotion research.
Areguy, F. Process and reflection on participatory action research with young carers in a community context

Action as Health Promotion

Lastly was the presence of an action orientation. Despite the ambiguity inherent in the process, the goal of producing something that would be used to advance the voices of young carers remained at the forefront of this project. In step with future health trends that suggest young people are becoming more active agents in health research (Galambos & Leadbeater, 2000), the YCP’s choice to adopt a PAR approach galvanized the health promotion aspect of the project. The input from young carers as co-researchers ensured that the resources created were ‘for young carers and by young carers’. The result was the creation of a guidebook called ‘Support Matters¹’, an accompanying documentary featuring young carers from the project, and a social media presence through an active website, facebook page, and twitter account (See Figure 1).

Figure 1: List of Social Media Sites for Young Carers Project

| Guidebook: https://goo.gl/oKVhTc |
| Documentary: https://www.youtube.com/watch?v=xFJ7Tp-Yx-w |
| Website: https://youngcarersproject.wordpress.com/ |
| Facebook: https://www.facebook.com/youngcarerswr/ |
| Twitter: https://twitter.com/youngcarersp |

These research-based resources are youth-friendly and accessible, and were freely disseminated through public education workshops led by myself and another researcher. These workshops and resources have been successful in raising young

¹ The ‘Support Matters’ guidebook is protected by copyright. However, permission is granted to individuals and facilities to reproduce specific pages for their own educational purposes and for not-for-profit purposes only. Hard copies of each guide can be ordered online by downloading an order form and mailing it to MAREP with payment, or calling the MAREP offices to place an order. The guidebook is available in English and French (hardcopy and PDF), as well as Spanish (PDF only): https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides
carer awareness and mobilizing the community to action. The YCP community collaborative expanded and led to many partnerships with local organizations, and the impact was measured in a recent follow-up environmental scan. This scan confirmed that more organizations and agencies were aware of young carers due to the efforts of the YCP. As of writing this, the most significant response has been from the City of Kitchener which started a dedicated Young Carer Peer Support program, joining the small handful of similar young carer programs that exist in Canada.

Conclusion

In sum, the Participatory Action Research process was an effective upstream health promotion tool for engaging young carers in community-based settings. The YCP created unique opportunities for young carers to create supports in community through translational research and public education, aiming to have a larger impact in preventing negative caregiver outcomes. I felt appreciated as a community asset during this process and played an active role in both the identification of young carer issues in Canada and the development of practical solutions to support them in my community.

References


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