



6-10-2018

# Parkinson's Disease Support Groups in Rural America: Barriers, Resources, and Opportunities

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### Recommended APA Citation

Bush, E. J., Singh, R. L., Hidecker, M. C., & Carrico, C. P. (2018). Parkinson's Disease Support Groups in Rural America: Barriers, Resources, and Opportunities. *The Qualitative Report*, 23(6), 1381-1400. Retrieved from <https://nsuworks.nova.edu/tqr/vol23/iss6/8>

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## Parkinson's Disease Support Groups in Rural America: Barriers, Resources, and Opportunities

### Abstract

People with Parkinson's disease who live in rural communities may lack information and support regarding their condition, compared to those in urban or suburban areas. For the study described herein, the researchers sought to gain a deeper understanding of support group experiences of rural Parkinson's disease stakeholders through merging an interpretive phenomenological design with Community-based Participatory Research (CBPR). Using this merged approach, we collected qualitative data from five focus groups to gain a community perspective. The qualitative data was analyzed thematically, first, and then further explored for an overall essence. The theme, Support Group Benefits: Opportunities for Communication expounded upon the importance of support groups to Parkinson's disease stakeholders. Barriers to Support Group Participation represented how the disease and the rural living conditions inhibited support group participation. Strategies to Improve Support Group Access demonstrated the different ways that the stakeholders had tried to overcome barriers and strengthen support groups. Notably, some participants discussed ways that support groups could increase their accessibility to more individuals with Parkinson's living rurally so that they endured as a future resource. The themes and accessibility recommendations that emerged led the researchers to interpret the overall essence of this work as, experiencing support group benefits despite barriers, leaving a legacy.

### Keywords

Community-Based Participatory Research, Support Groups, Parkinson's Disease, Focus Groups, Qualitative Research, Interpretive Phenomenology

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### Acknowledgements

We thank the Parkinson's stakeholders who shared their perspectives and experiences with us. Focus group moderators or co-moderators (in addition to the authors who served as moderators) were Rex Gantenbein, Christopher Herron, Beth Young Jones, Judith Powers, and Sandra Sundin. Transcriptionists included Katelynne Adams, Clarissa Petres, Brittney Arevalo, Allison Long, Bree Olson, Adele Riley, and Noel Schatz. We also thank the coordinators of the Wyoming Parkinson's Project, Sandra Sundin and Christopher Herron.

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The luncheon, travel, and accommodations for participants were paid for through a Patient Centered Outcomes Research Initiative (PCORI) Pipeline to Proposals: Tier III Grant. This PCORI award also paid student research assistants for their time transcribing.

## **Parkinson's Disease Support Groups in Rural America: Barriers, Resources, and Opportunities**

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*People with Parkinson's disease who live in rural communities may lack information and support regarding their condition, compared to those in urban or suburban areas. For the study described herein, the researchers sought to gain a deeper understanding of support group experiences of rural Parkinson's disease stakeholders through merging an interpretive phenomenological design with Community-based Participatory Research (CBPR). Using this merged approach, we collected qualitative data from five focus groups and gained a community perspective. The qualitative data was analyzed thematically, first, and then further explored for an overall essence. The theme, Support Group Benefits: Opportunities for Communication expounded upon the importance of support groups to Parkinson's disease stakeholders. Barriers to Support Group Participation represented how the disease and the rural living conditions inhibited support group participation. Strategies to Improve Support Group Access demonstrated the different ways that the stakeholders had tried to overcome barriers and strengthen support groups. Notably, some participants discussed ways that support groups could increase their accessibility to more individuals with Parkinson's living rurally so that they endured as a future resource. The themes and accessibility recommendations that emerged led the researchers to interpret the overall essence of this work as, experiencing support group benefits despite barriers, leaving a legacy. Keywords: Community-Based Participatory Research, Support Groups, Parkinson's Disease, Focus Groups, Qualitative Research, Interpretive Phenomenology*

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Motor problems such as balance problems, bradykinesia, and rigidity of movement are often considered the hallmark symptoms of Parkinson's disease (PD); however, individuals also contend with many non-motor symptoms (e.g., fatigue, cognitive problems, and autonomic nervous system changes; Olsson, Strafström, & Söderberg, 2013). While all of these challenges make living with Parkinson's difficult, psychosocial aspects, particularly the need for emotional support, are often cited as one of the most problematic (Kleiner-Fisman, Gryfe, & Naglie, 2013). Additionally, more family support does not predict less psychological stress (Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006). Per Simpson et al. (2006), the predictive power for less psychological distress was related to having satisfaction with the social support that patients with PD experienced rather than the amount of support. Whereas constructs such as self-esteem and happiness were possibly influenced by the amount of support available (e.g., number of close relationships). Thus, belonging to a disease-based support group, particularly to cope with psychosocial aspects of the condition, is an important aspect for many people with Parkinson's (Artigas, Striebel, Hilbig, & Rieder, 2015; Lieberman, Wizlenberg, Golant, & Di Minno, 2005; Nishida, Ando, & Sakakibara, 2012).

The need for resources is particularly problematic in rural areas, where proportionately more elderly people have less access to healthcare than in the rest of the United States (Dorsey et al., 2010). While a drastic upsurge in adults 65 years and older is expected in the US

population as a whole, rural areas will see the greatest influx of this age group (Baernholdt, Yan, Hinton, Rose, & Mattos, 2012; Merchant, Coussens, & Gilbert, 2006). People living rurally also have a disproportionate rate of chronic disease and poorer health in general (Coward, McLaughlin, & Duncan, 1994; Cromartie & Nelson, 2009; Hart, Larson, & Lishner, 2005), as well as a greater likelihood to be impoverished (Rosenblatt, 2001). Therefore, individuals with Parkinson's who live rurally face considerable challenges with disease management because in rural locations individuals have poorer health, less access to healthcare, and lower incomes than their urban and suburban counterparts do. Less access to healthcare in rural areas is usually due to fewer providers in general, as well as fewer specialists (Dorsey et al., 2010).

### **Purpose**

Current knowledge in the field of Parkinson's disease support groups has been acquired using quantitative methods examining on-line support group effectiveness for people with Parkinson's (e.g., Lieberman, 2007) and their caregivers (Marziali, Donahue, & Crossin, 2005). Qualitatively, Attard and Coulson (2012) conducted a qualitative thematic analysis of patient communication in on-line support groups, and Bramley and Eatough (2005) conducted a phenomenological study with individuals with Parkinson's. However, none of the aforementioned studies focused on rurality or face-to-face support groups. While the researchers who conducted the two qualitative studies did employ thematic analyses, as we did, neither used focus groups, and the one phenomenological study did not seek an overall essence, as we did. Finally, one qualitative study we found used thematic analysis and sought the perspectives of people with Parkinson's, their caregivers/family members, and professionals, through focus groups, as we did; however, they did not seek perspectives of rural individuals, specifically, and conducted their study internationally. To our knowledge, no qualitative research exists about Parkinson's support groups that targets the perspectives of rural individuals using focus group data collections. Further, we do not believe that an interpretive phenomenological lens or analysis has been used in conjunction with community-based participatory research, like ours.

Thus, the purpose of this study was to understand better the experiences of the Parkinson's disease community in a rural state. We used qualitative data collection and analysis so that we could gain stakeholders' in-depth experiences and perspectives with Parkinson's disease, and we used focus groups to do so. In response to broad, open-ended questions, and our initial identification of significant statements, it became apparent that support groups were a substantial focus for the participants of this study. The potential role of support groups was certainly considered beforehand, but we underestimated how significant the role of support groups would be. Other aspects of experiencing Parkinson's disease in a rural location emerged from the focus groups, as well. However, only the experiences regarding support groups emerged in such a way that warranted a phenomenological analysis and description, due to the level of importance participants placed on them, the frequency with which they emerged from the data, and the rich contexts with which they were described. Other aspects about the Parkinson's stakeholders' experiences emerged, such as their use of healthcare providers, whether they saw specialists or generalists, whether they utilized allied healthcare professionals for disease management, among others. However, due to the prominence and volume of support group experiences shared, the purpose of this paper is to describe only the essence of the support group experiences. Thus, the following sections elucidate the specific methods, data collection, data analysis, and results for support group experiences. Other aforementioned thematic findings, not pertaining to support groups specifically, are described in a separate manuscript (Singh, Bush, Hidecker, & Carrico, 2018).

## **Research Aim: To Achieve a Deeper Understanding of the Parkinson's Stakeholder Community's Experiences with Support Groups in a Rural State**

All authors have established ties to the provision of health care services. Researchers, EB and MJCH, formerly worked clinically with people with communication disorders. RS is a social pharmacist and CC works as director of a state center on aging. Collectively, all the authors valued patient advocacy and sought to maintain a patient-centered perspective with focused efforts on clinically applicable research. All four authors worked closely with the community researchers on this project, which also connected us on a more personal level to the research outcomes. All researchers on this project aimed to establish action points to enhance access to community resources and ultimately improve services for people with Parkinson's. While we did not practice bracketing, given the interpretive/hermeneutic phenomenological approach used (Smith, 2008), the researchers did practice self-reflexivity throughout the study. This, coupled with the research methodology of CBPR, in our opinion, enhanced the findings as we sought to reflect the most authentic results for the people with whom we had been working closely.

### **Methods**

#### **Participants and Sampling**

The appropriate university Institutional Review Board (IRB) approved this project and the researchers complied with all IRB requirements. Specifically, participants were informed about the study purpose, the activities required for participation, and that they have the right to ask questions of the researchers and/or the IRB, and that their participation was entirely optional, and they could withdraw at any time.

Thirty individuals participated in five focus groups. Each group consisted of individuals with various types of stakeholder roles (i.e., persons with Parkinson's, caregivers, professionals). A solicitation for participation in the study was sent through a state-wide Parkinson's disease newsletter. Recipients of the newsletter included people with Parkinson's, family members or caregivers of someone with Parkinson's, or any healthcare provider who worked with people with Parkinson's disease. The statewide network, through which the newsletter was delivered, was formed prior to this research study in an attempt to unify Parkinson's stakeholders throughout the state. Its purpose was to develop a community of individuals focused on deriving support for, treating, researching, educating, and/or learning more about Parkinson's.

The newsletter informed readers about a free luncheon meeting, located in a central part of the state, which all stakeholders were welcome to attend. The luncheon meeting was held to inform Parkinson's stakeholders about the network's accomplishments and future goals, and individuals were invited to stay for the focus groups at the end of the luncheon if they chose to do so. Participants were invited to attend via video chat if they could not attend in person. Focus groups each had four to nine individuals, including the one focus group conducted by video chat. A moderator for each group presented general open-ended questions and asked follow-up, context-dependent questions.

#### **Design**

The study was designed for the focus groups to reflect "mini-communities," as the researchers pursued representations of community interactions and perspectives with diverse

stakeholder backgrounds. That is, focus groups consisted of people living with people with Parkinson's, family members and caregivers of people with Parkinson's, as well as health care providers (e.g., psychologists, physicians, physical and occupational therapists, speech language pathologists, and pharmacists). We used a philosophical and qualitative approach, interpretive/hermeneutic phenomenology. In addition, we used a community-based participatory research approach. We believed that community-based engagement methodology was the most natural way to conduct a study that sought to understand a community. While engagement principles were intrinsic to the design of our study and incorporated throughout, they can be summarized in the following table.

Table 1. Community-based Participatory Researcher Roles

Stage of Research	University researchers	Community organization	Stakeholders from the Parkinson's' community	Student research assistants
Study Design- establishing the research question	✓	✓	✓	
Focus group guide development	✓	✓	✓	
Participant Recruitment	✓	✓		✓
Moderating of focus groups	✓	✓	✓ (moderators & co-moderators)	✓ (co-moderators)
Focus group transcription				✓
Proofreading & Checking of transcription	✓	✓	✓	✓
Data analysis	✓			✓
Member checking	✓		✓	
Dissemination (on-going)- various roles	✓	✓	✓	✓

We maintained an “open phenomenological attitude” (Finlay, 2009) throughout the study, which allowed unanticipated meanings to be discovered (Giorgi, 2011; Lopez & Willis, 2004). However, some a priori assumptions were inherent to the study because in keeping with a CBPR approach, community researchers' views were sought prior to developing research questions, and both the academic and community researchers developed the interview protocol. The community researchers felt strongly about the question topics they wanted posed in our focus groups; and because they were also stakeholders, their views added authenticity to these questions. We selected a data analysis method that allowed for a priori themes, which is further explained in our *data analysis* section. Inductive methodology, in our study, is evidenced by the evolution from our initial purpose, a general inquiry into stakeholders' experiences with PD in rural communities, to a specific analysis of their experiences with support groups. This is described previously in the *Purpose* section. Inductive, social constructionism led us to appreciate the heavy-weighted support group data and allowed us to evolve our purpose and analysis process to reflect this. The underlying philosophy of interpretive/hermeneutic phenomenology is that experiences are not a conclusive truth, but rather they are socially

constructed, and inherent in expressing them is the researchers' interpretation. In our case, our interpretation was constructed through the multiple perspectives of the researchers. The data, gathered through focus groups, designed as miniature communities of Parkinson's disease stakeholders, were both socially constructed and represented the lived experiences of Parkinson's disease stakeholders. We followed the guidelines and referred to the work of Finlay (2009), who recommended that researchers of human sciences, particularly those practicing phenomenology, should "recognize that any knowledge produced is contingent, proportional, emergent, and subject to alternative interpretations" (p. 17). Moreover, when using an interpretive phenomenological lens, one does not seek an absolute true representation of people's experiences. Rather, it is "focused on subjective experience of individuals and groups [attempting] to unveil the world as experienced by the subject through their life world stories" (Kafle, 2011, p. 186). Therefore, following our thematic analysis, we sought to uncover and represent an essence that signified the stakeholders community's perspective.

Two of the authors (EB and MJCH) were speech-language pathologists and had both worked clinically prior to their research careers, and they placed specific emphasis on participants' ability to communicate. Parkinson's disease can disrupt a person's speech intelligibility and/or ability to write legibly. To ensure that each person with Parkinson could be "heard," the researchers provided paper/pen to write and *alphabet communication boards* to spell out words. However, the persons with Parkinson's either had intelligible speech or came with a significant other who interpreted what they said or wrote. Notably, some of the participants asked to take the *alphabet communication board* home after the conclusion of the focus groups, and we allowed them to do so. Having alternative methods of communication available should send the message to participants with Parkinson's disease that we want to "hear/read" their thoughts and we will wait for the time it takes to use these alternative communication methods. This may lead to more authentic data from the person with the speech difficulty because he sees that we will wait for him to compose his message either by writing or pointing to letters on the alphabet communication board to spell out his message. Speech-language pathologists who are specialists in augmentative and alternative communication use these as common strategies. We have not seen this described in the Parkinson's disease research. However, this has been done in research in augmentative and alternative communication.

## Procedures

Focus groups were held after the luncheon meeting and after allowing time for unstructured conversation, to create a more open atmosphere for sharing. The fifth focus group consisted of four individuals who opted to participate through video chat, who also had time for unstructured conversation before participating in the focus group interviews. These semi-structured interviews, along with field notes from the facilitators, were the primary source of data collection. The facilitators used a pre-determined interview guide that consisted of open-ended questions (e.g., Overall, what barriers exist in improving the quality of life of patients with Parkinson's in [this community]? What resources and programs are already in place in [this community]?) that were context-dependent and varied as necessary (Creswell, 2013).

## Data Analysis

Despite collecting data on a wider topic area than just support group experiences, after immersion in the data, the robustness of the support group experiences became apparent, and the magnitude of the support group data certainly warranted its own data analysis and results. Thus, we honed our focus to seeking a representation of the meaning of the stakeholders' lived



experiences specifically with Parkinson's support groups. Other notable data about the general inquiry of experiences is published elsewhere (Singh et al., 2018).

Research assistants transcribed the focus group interviews verbatim from audio recordings. The transcriptions were analyzed by the researchers, first, through immersion in the data and hand-coding, and were later organized using NVIVO 10® software. This software is commonly used amongst qualitative and mixed methods researchers (e.g., Houghton, Murphy, Shaw, & Casey, 2015; Ivankova, 2014), particularly in health science research (Woods, Palus, Atkins, & Macklin, 2016). This process was similar to what Sohn (2017) described, in that, the software was not used to analyze the data, per se, but rather it provided a central location for the researchers to organize data, conduct some stages of the coding process, and communicate with one another through comments and notations. Initially, we noted key statements and descriptions of stakeholder experiences, but our goal remained to find whether there was consensus of focus group participants because we sought to understand the lived experience of the *community*. The interconnectivity of the disease process and utilization of support groups, as well as changes over time cannot be underestimated and justifies the need for an approach that appreciates both openness and relational aspects of the findings. We asked that participants relay their experiences and perspectives in a group setting. There was remarkable agreement between individual participants, as well as across focus groups about all topics covered, particularly regarding aspects of their rurality. This consensus led us to consider (and eventually XXX) the *community* perspective of Parkinson's stakeholders. We conducted two major types of analysis. Thematic analysis was carried out using Template Analysis (see explanation below). Following, we re-examined the themes and explored them for an overall essence, going back and forth from concepts that we felt were represented, to data in the transcripts and themes, continually ensuring their applicability and authenticity.

We did not seek causal explanations or justifications for an extant theory, hypothesis, or framework. Rather, we conducted the analysis inductively. Even the a priori categories, largely determined by the community researchers, underwent analysis to ensure their fit and conceptual importance. In analyzing the data, both the Template Analysis process and the search for a collective essence was carried out by utilizing the *hermeneutic circle*. The hermeneutic circle can be thought of as an iterative process (Ajjawi & Higgs, 2007) used to balance and appreciate both the data as well as the researchers' interpretation of the data, gaining new knowledge at multiple points (Debesay, Nåden, & Slettebø, 2008). The researchers' focus should be continually brought back to the data, lived experiences, which should in turn result in new or deeper understanding from the researchers, enhancing their interpretation (McConnell-Henry, Chapman, & Francis, 2009). This process, often thought of as a spiral, is an evolution of both understanding and interpretation of lived experiences (Debesay, Nåden, & Slettebø, 2008). In keeping with the hermeneutic circle and a constructivist paradigm, we maintained openness throughout the analysis. Specifically, throughout our practice of the hermeneutic circle we conducted on-going discussions between the researchers. These encompassed the researchers' reflexivity insights, views, and disagreements regarding data coding. All disagreements were resolved through discussion and/or by clarifying theme descriptions. The development and further clarifications of themes was conducted through Template Analysis.

Template Analysis is a thematic way to code qualitative data that has a history of application to health care research (King et al., 2013; McCluskey, Brooks, King, & Burton, 2011), and can be adapted to many types of epistemological views (King, 2004). The flexibility of this type of analysis fit well with our research paradigm of social constructivism and interpretivism (King, 2004). Further, Template Analysis applies favorably to both narrative and phenomenological studies where the reliability of coders is less important than principles

such as researcher reflexivity, evolving concepts, and descriptions of lived experiences (King, 2004).

Template Analysis also allows researchers to include a priori themes, when necessary, such as when known concerns need to be incorporated (Brooks, McCluskey, Turley, & King, 2015). Therefore, an additional reason this analysis was chosen was because our study had two a priori themes. Our justification for using these themes is rooted in our CBPR approach. Both the concept of *Resources* and *Barriers* were deemed important by our community researchers (and stakeholders) and were included in the interview protocol. To describe the use of a priori themes, in Template Analysis, Brooks and colleagues (2015) stated,

*A priori* themes are equally subject to redefinition or removal as any other theme should they prove ineffective at characterizing the data. However, the selective and judicious use of a prior themes can allow researchers to capture important theoretical concepts or perspectives that have informed the design and aims of the study. . . . (p. 218)

The a priori themes established and analyzed in this study are addressed in our *Results* section.

Following the template analysis, we searched for an overall, collective or community, essence. We went back to the data, revisiting and questioning the themes and their definitions, as well as our thematic analysis of them. We re-examined their organization, and illustrative quotes, and then circled back to a holistic view of the data. This process was repeated—each time gaining insight—similar to our previous use of the hermeneutic circle. A discussion of the overall essence is presented in *Results*.

Trustworthiness and rigor were ensured by on-going discussion amongst the two qualitative expert authors (EB and RS) and cross-check of the template and final themes by the other researchers involved in the study, as well as the practice of reflexivity throughout. We conducted member checking at a follow-up luncheon, where the themes were shared and discussion about them was encouraged.

## Results

### Thematic

Participants were asked general, open-ended questions that repeatedly inspired discussions about support groups. The questions pertained to resources/programs for people with Parkinson's disease, as well as barriers they had experienced. Again, overwhelming consensus emerged across all topics, leading us to conceptualize our findings as a community perspective. Initially, responses about support groups fell into two broad categories directly related to the question topics, existing *resources* and *barriers*. However, data analysis revealed further details about these basic concepts and also revealed an unanticipated result about ways that stakeholders had tried to improve support groups access.

**Template Analysis and Template Creation.** Our steps for developing and revising our template, and then ultimately defining and naming our themes was as follows.

Step 1. *Immersion in the data corpus:* Our collective a priori assumptions led us to believe there would be aspects of both barriers and resources that would be important. The community researchers informed the designing of our interview protocol questions. Questions targeted barriers and resources, so unsurprisingly our initial over-arching themes seemed to be *barriers* and *resources*. However, *possibilities* also emerged as an over-arching theme despite that we did not explicitly ask about them. Thus, we initially designed a template using:

- 1a. Barriers
- 1b. Resources
- 1c. Possibilities

Step 2. *Continued Immersion*: As data immersion continued and we searched through the transcripts for Barriers, Resources, and Possibilities we entertained further refinement. Resources seemed to be better classified as *Benefits* given their overwhelming positive nature and the fact that focus groups often defined them as such. These were levels at which PD and rurality intersected and affected:

- 2a. Healthcare Systems Level
- 2b. Community/group Level
- 2c. Individual/patient Level

Step 3. *Combining Concepts*. Combining these two previous conceptual groups, we began to explore the transcripts using both levels 1 and 2 above:

- 1. Benefits
  - a. System level
  - b. Community level
  - c. Individual level
- 2. Barriers
  - a. System level
  - b. Community level
  - c. Individual level
- 3. Possibilities
  - a. System level
  - b. Community level
  - c. Individual level

Step 4. *Re-analysis of Template*. After searching the transcripts and re-evaluating our 2 conceptual frameworks, we found that this multi-level template fit in some areas and not in others. *System level* issues, for example, were sparsely represented and did not appear to bear significance to the overall purpose of the study. Additionally, *possibilities* appeared to be its own entity separate from the *system*, *group*, and *individual* level categories.

Step 5. *Revised Template Development*. Next, we eliminated extraneous concepts that did not fit. Thus, the following template arose:

- 1. Benefits
  - a. Community/group level:
  - b. Patient Level
- 2. Barriers
  - a. Community/group level:
  - b. Patient Level
- 3. Possibilities

Step 6. *Themes Determination*. After identifying the above, relevant concepts, we analyzed all focus group transcripts by the above template. After reviewing the codes, significant

statements, and illustrative quotations, we renamed and refined them to be more representative of the data. This process generated our final *overarching themes* and *subthemes*:

1. *Benefits* became ***Support Group Benefits***
  - a. Community/group level: *Disease Education*
  - b. Patient Level: *Emotional Support*
2. *Barriers* became ***Barriers to Support Group Participation***
  - a. Community/group level: *Barriers to joining*
  - b. Patient Level: *Barriers to attending*
3. *Possibilities* became ***Strategies to Improve Support Group Access***

The three main themes and four subthemes that helped to both expose and explain the overall essence of the Parkinson's community's experience with support groups are found in Table 2.

Table 2. Essence and Theme Descriptions

<b>Essence:</b>	<b><i>Experiencing support group benefits despite barriers</i></b>
<b>Theme:</b>	<b>Description and Subthemes:</b>
<b>1. <i>Support Group Benefits: Opportunities for Communication</i></b>	Identified and elucidated stakeholders' experiences with the existing resources; two subthemes were: <ul style="list-style-type: none"> <li>• <i>Disease education</i></li> <li>• <i>Emotional support</i></li> </ul>
<b>2. <i>Barriers to Support Group Participation</i></b>	Explained the barriers participants experienced, as well as speculations about barriers others might experience; two subthemes were: <ul style="list-style-type: none"> <li>• <i>Barriers to joining</i></li> <li>• <i>Barriers to attending</i></li> </ul>
<b>3. <i>Strategies to Improve Support Group Access</i></b>	Described participants' experiences with trying to increase participation in support groups

The community perspective was obtained through vast consensus across focus groups and focus group members, however, in the few instances when consensus was not initially present on a particular topic, we have noted it specifically in the following theme and subtheme descriptions.

### **Support Group Benefits: Opportunities for Communication**

Participants discussed their experiences with specific support groups they had attended and shared their opinions about them. Overall, statements indicated that participants felt the groups were beneficial because of the opportunities for communication that they provided. Notable concepts and keywords that arose from discussing the benefits of interacting with other support group members were, education, idea-trading, "connection," "interaction," and "emotional support." Support groups increased opportunities for communication with others, specifically through two key aspects. These were organized into two subthemes, (a) *Disease education* and (b) *Emotional support*.

**Disease Education.** Many participants noted positive experiences of both sharing and attaining information within their support group. They discussed the benefit of being able to talk with other people with Parkinson's and their family members, as well as having health care professionals give educational presentations about different aspects of the disease or disease management. Some groups experienced ease of scheduling professionals to speak to their

groups, while others did not, but all seemed to agree that guest speakers benefitted support group members. Participants noted that support groups also provided a way for members to share suggestions and education about symptom management through their personal experiences.

One support group member stated, “Our support group, I would say it’s working, and [others] were saying [their] support group is working. It’s a lot of work, but it’s working.” When probed further about why their support groups are “working,” several individuals indicated that the facilitation of communication between persons with PD and caregivers was extremely valued. A caregiver focus group member stated, “I think it’s the interaction between the patients with Parkinson’s, where they can talk about the different symptoms they have and maybe somebody will suggest something that works for them that we never thought about.”

**Emotional Support.** Another benefit to support group participation was interacting with people who had faced similar challenges and situations and the potential for gaining emotional support from one another. A benefit strongly implied in the focus groups was that participation in support groups decreased the experience of isolation for people with Parkinson’s and their caregivers. One support group, that traditionally met once a month, decided to form an additional weekly exercise group. A few participants gave this collective description of the group, “There is a therapy group here, or exercise group where they get that comradery...and laugh at each other...*with* each other.” Clearly, the support group provided an opportunity for a spin-off group to address a common need of its members and ultimately provided members with more than just an opportunity to exercise. These highly valued experiences of emotional support were derived from talking to others contending with the same types of problems. This specific level of comfort could not be found with people outside the Parkinson’s community because even individuals contending with other types of neurological problems, could not understand Parkinson-specific struggles.

## Barriers to Support Group Participation

While participants made many positive statements regarding existing support groups, several problems and challenges had been experienced as well. These were classified as *Barriers to Support Group Participation*, but further classified into barriers to either *joining* or *attending* support groups. Participants discussed specific problems as well as general concepts to explain why individuals may choose not to join a support group, as well as deterrents to attending a support group they had already joined. These two types of barriers were classified as the subthemes, *Barriers to joining* and *Barriers to attending*.

**Barriers to Joining.** This subtheme illustrated experiences of persons with Parkinson’s not joining support groups or experiencing why it was difficult initially, even though they eventually chose to join one. Regarding their personal experiences, participants described barriers by expressing frustration on two main fronts. First, if people were part of an active support group that later disbanded, former members were hesitant to join the *new* group. New groups were described as taking a long time to “get one going again.” Indicating that people needed to try to keep current support groups going, and not allow them to disband. A related frustration was with not gaining new members despite widely publicizing support group meeting details.

Suppositions as to why other people with Parkinson’s may not join, also came up frequently, and despite not being *personal* experiences, were not dismissed because they were still deemed representative of the Parkinson’s community’s experience. Participants stated that some individuals with Parkinson’s know about the support groups and simply do not want to attend. “You find people in denial, I mean, they have got Parkinson’s in beginning stages and they don’t want to admit it, so they won’t go to a meeting.” This idea prompted others to discuss

their or their spouse's apprehension with initially joining. Likewise, one participant cited an interaction with a person with Parkinson's, stating "One woman told us that she's young. It could be because we have it at the senior center, but she said she doesn't want to go and be exposed to people who are further along in the disease because it scares her. It just causes negative feelings, so she doesn't want to go." Regarding meeting locations, other participants discussed meetings held at senior centers, a popular location for several groups. While benefits (e.g., no building fee, free advertising to attract new members) were noted, participants also acknowledged that meetings held there could discourage potential members who are not seniors.

**Barriers to Attending.** Participants gave several reasons why they had or have had difficulties in the past, with attending support groups regularly. The majority of statements in this subtheme centered on the rurality and remoteness of the state. Individuals discussed the lack of support groups, which consequently often required people to drive long distances to their nearest support group. "We don't have enough support groups in this state. As I mentioned earlier, people drive 80 miles to go to our support group." Participants noted that needing to drive long distances limited attendance, particularly when weather conditions made travelling hazardous or more time-consuming than usual. People noted specific information about active support groups often being in the corners of the state, making them even less accessible to people located elsewhere, and the need for more centrally located groups.

Many participants experienced meeting locations and times as a hindrance to their regular attendance as well. Participants discussed difficulties with scheduling meetings for all potential members including those who are employed and those who are retired. Specifically, meeting times were cited as potentially limiting to working professionals if they were held during the day, yet older adults experienced difficulties with attending evening meetings due to difficulties with driving in the dark or disrupting usual mealtimes. One support group member explained, "Some of our [members] are older ladies, and they don't want to drive at night, so you have to have it before, in wintertime, 4:30 [PM]."

### **Strategies to Improve Support Group Access**

Focus group participants stated ideas about how to address some of the barriers, foster increased membership to existing groups, and improve support group access. Specifically, two main concepts emerged. First, several individuals suggested ways to promote more local support group participation and/or ways to engage more PD stakeholders throughout the state. Recommendations were based on their own support groups' current practices, as well as ideas about future statewide engagement, which may consequently encourage increased support group membership. Secondly, several group discussions centered on alternative ways to hold support group meetings in the future to improve access

Individuals actively involved in their local support groups shared ways they have tried to support increased attendance and membership. Strategies emerged from the focus groups into general about how to engage more people statewide to strengthen the Parkinson's disease stakeholder network. These included ideas about adding material from each support group's meetings in the statewide newsletter and on a website. Participants also suggested that posting content from each group meeting, particularly when there were professional speakers, would give ideas to other groups, and possibly attract more members. These suggestions largely focused on how to communicate about the groups' meeting times and locations. One member stated, "We took fliers to beauty shops. They know more about what's going on in town than anybody." Suggestions about encouraging more memberships largely focused on how to advertise groups' meeting times and locations. Several similar ideas and strategies to the

introductory quote arose, and individuals discussed publicizing support groups through medical professionals, and discussed the best times and locations to have meetings.

Focus group discussions also included ideas about how to engage more people statewide to create a network of Parkinson's disease stakeholders and, as a result, increase support group participation. Ideas included starting a statewide newsletter and/or a website to communicate information about the support groups as well as other events across the state for Parkinson's disease stakeholders. Participants also suggested that a newsletter should include support group meeting information, as well as content from each group meeting to give ideas to other groups, and to attract more members. Some participants felt that the latest research about PD and other resources for information should be included. One individual summed up his/her focus group's discussion, while promoting statewide, stakeholder collaboration, by saying, "So yeah a newsletter, the support groups could trade ideas just by putting in [who] our speakers are...I could write something on how to recruit people to your support group, and maybe the University could do a research project on that group." From the sharing of these experiences, the researchers made the collective judgement that many of the stakeholders believed publicizing meeting content could potentially make attending a first meeting less daunting.

An alternative method of improving support group access notably emerged from the data as well. That is, online support groups emerged as a potential solution to many of the rural barriers expressed. This was not deemed thematic content in the results, as it was not an *experience* of our rural Parkinson's community. Additionally, differing opinions were expressed, and a community perspective was not initially present. Focus group participants expressed mixed feelings on the issue of online support groups. Some participants felt that this was a viable option, while others expressed apprehension with using technology for people with Parkinson's, particularly because of the likelihood that those with Parkinson's disease are 65 and older, and may, therefore, have more struggles with using technology, than younger individuals. This was reflected in a significant statement and subsequent conversation amongst stakeholders. "A lot of senior people aren't technically savvy to use a computer. I mean I wouldn't feel comfortable doing that." However, after three other focus group members gave other suggestions about increasing confidence with using technology, the individual ultimately agreed that he/she would feel comfortable going to a clinic or another public location, such as a library, to access online resources, where technical support could be available when needed. This interaction was representative of the rural Parkinson's community as it, again, implied the importance that support groups held with this population, and suggested the importance of community resources.

## The Essence

We searched for an essence through both re-examining the established themes, but also returning to the illustrative quotes, and the entire data corpus (transcripts and field notes). Participants offered advice and recommendations during the focus groups about how to engage more stakeholders in other communities. Advice and recommendations were based on the participants' own attempts to encourage more membership in their communities, and despite that they were disclosed as advice, they arose from participants' experiences. Additionally, the fact that these experiences were represented as advice to others implied how important participants felt that support groups were. While reflecting on their experiences in context, and how they chose to share their experiences what struck was not *what* they were sharing regarding *Strategies to improve support group access*, but *how* they shared them and *why* they shared them in this way. They were, after all, toward the end of their lives, struggling through a disease process that worsens until end of life. Yet they still thought about *possibilities*. Our holistic

interpretation of this data was: because these individuals were toward the end of their lives, and most of them knew they would not see changes made to support groups in their lifetime, they were making recommendations, as possibilities, for future members. These experiences constituted the researchers' most unanticipated results and are essential to the overall essence of this research. They helped illustrate that despite the considerable barriers, members persevered to keep their support groups active. The researchers interpreted this persistence as members' desire to leave a legacy and ensure their support groups would continue even after they were gone.

Another important aspect during our search for an essence was that the benefits of support group experiences appeared to outweigh the barriers to attending them, for this rural community. In fact, Parkinson's disease stakeholders not only expressed determination to ensure their own support groups prospered, but also a desire to strengthen other groups across the state. Notably, these latter experiences usually emerged in the form of recommendations to other stakeholders or to the researchers, which was key to the essence of this work. The fact that this was presented as advice delineated just how much the community wanted support groups around the state, to thrive, and that their reflections were not simply based on their own self-interest, or that of their family member, patient, etc. This community indicated that their desire was for support groups to persist even after they were gone. Thus, the essence of this rural, Parkinson's community's experience with support groups can be described as *experiencing support group benefits despite barriers: leaving a legacy*.

## Discussion

This study explored the experiences of Parkinson's disease stakeholders regarding support groups in a rural state. The findings reported herein have the potential to influence other PD stakeholders, including people with PD, their family members or caregivers and future practitioners. Both benefits and barriers were discussed and potential ways to address the barriers emerged. Policy makers may also consider the findings addressing amelioration of barriers for rural people with chronic health conditions, to make support groups more accessible.

In general, the benefits experienced were increased communication with other individuals with Parkinson's, caregivers, and/or healthcare providers, as well as emotional support gained. These findings are consistent with past research. In a recent survey of 726 Americans with Parkinson's, 61% had attended a support group at least one time, and 49% reported a high satisfaction rate with information received from other group members as well as the group leader (Dorsey et al., 2010). Researchers have found that people with Parkinson's disease who participate in support groups, compared to those who do not, have higher quality of life scores and lower depression, anxiety, and social phobia (Artigas, Striebel, Hilbig, & Rieder, 2015). For people with Parkinson's living rurally with limited healthcare access, support groups can provide a source of emotional support as well as access to information.

Focus group participants described their experiences (or relayed other's experiences) with barriers to support group participation. Generally, barriers encompassed two main ideas, rurality and meeting details. Participants expressed that barriers could prevent new members from joining and hinder attendance for existing members. Rurality appeared to be a barrier to joining and attending support groups because of the lack of groups (due to low population) and drive time combined with weather conditions. These barriers were consistent with other research findings (Lieberman, Wizlenberg, Golant, & Di Minno, 2005). Interestingly, similar barriers of accessibility and the need for transportation were found by Dorsey and colleagues (2010) for participants in both rural and urban areas. Specifically, travelling takes longer and is a considerable burden for many people with Parkinson's, regardless of their urban or rural



setting, due to the movement difficulties associated with the disease. Additionally, as the general Parkinson's patient population is elderly, they may be more likely to experience injuries when traveling or walking in harsh winter conditions and therefore, more apprehensive about travelling in general.

Although not discussed, attrition rates due to Parkinson's mortality could be a potential barrier to joining and attending disease-based support groups. For example, individuals may not join or stop attending due to the deaths of their friends, or entire groups may disband based on the high rate of attrition. Not only will members of the groups ultimately die, but other members may likely become disheartened and not wish to keep meeting new members. In one study, members of Parkinson's disease online support groups that dropped out after ten sessions or less, had higher anxiety about death than those who continued to attend (Lieberman, 2007). Thus, support group members who are fearful of the disease progression and/or death may be less likely to join. If they do join, they may be more likely to stop attending based on their fears or the death of other members.

Active support group members expressed their desire to increase membership and access to Parkinson's support groups. They described their experiences and the strategies with attempting to do so. Successful strategies were shared in the form of advice to other focus group members. Some of these included better publication of meeting times and locations, utilization of guest speakers to provide further education, and more widespread dissemination of meeting content.

Previous research cites many benefits to internet resources designed for people with disabilities (Cummings, Sproull, & Kiesler, 2002; Guo, Bricout, & Huang, 2005). Some resources (e.g., online disease-specific chat groups) seem to not only provide a means of information exchange but also appear to promote feelings of community that may positively affect people's sense of well-being. Additionally, because internet resources can reach many individuals with similar challenges, another benefit is that individuals can connect with one another regardless of their geographical location. Further, on-line resources may also serve as a safeguard against negative emotions frequently felt by individuals with disabilities (e.g., isolation, loneliness, stress, anxiety, depression; Obst & Stafurik, 2010).

In the current study, specifically, online support groups emerged as potential solution to the barriers discussed by participants. This proposed solution is one the researchers deemed worthy of pursuing in future research endeavors and has previous support in the literature. The capability for health-based, online support groups to address several barriers discussed herein was corroborated by past research (Dorsey et al., 2010). Individuals have the ability to join specialized support communities with potential anonymity and without geographical barrier (Finfgeld, 2000; Finn, 1999; Klemm, Reppert, & Visich, 1998; Salem, Bogar, & Reid, 1997; Wright, 2002). Online groups are typically free of cost (except for possible web access and web-enabled technology) and available 24 hours a day (Finfgeld, 2000; Finn, 1999; Klemm, Reppert, & Visich, 1998; Salem, Bogar, & Reid, 1997). Additionally, no limit exists on how often an individual can participate (Klemm, Reppert, & Visich, 1998), and after a period of inactivity, members can access what they missed (Wright, 2002). Finally, patients can "lurk" in online groups to judge the fit of the group or obtain vicarious support without ever disclosing personal information (Klemm, Reppert, & Visich, 1998; Merchant, Coussens, & Gilbert, 2006; Preece, Nonnecke, & Andrews, 2004). People would not need to travel in dangerous weather conditions or at night. Employed individuals may find online groups easier to schedule, as would other members if attendance did not require extra travel time. Without a formal location and more accessibility to meetings, younger individuals may be more likely to attend, and specifically-targeted meetings could occur (e.g., meetings for younger people with Parkinson's disease, caregiver meetings, meetings for those recently diagnosed).

Specialized meetings may remedy specific barriers such as, people recently diagnosed with Parkinson's not wanting to meet others with more advanced Parkinson's, finding it disconcerting or frightening to know what lies ahead. Furthermore, past research demonstrates that people with Parkinson's who belong to homogenous groups such as those based on age or time since diagnosis, are more attracted and committed to their group and experience increased positive outcomes (e.g., lower depression scores and higher quality of life) on pre-post measures of online support group participation than those who belonged to heterogeneous groups (Lieberman, Wizlenberg, Golant, & Di Minno, 2005).

### **Limitations and Challenges**

The purpose of this study was to describe the support group experiences of rural Parkinson's disease stakeholders. Because of the nature of the focus group interviews, participants not only self-selected to participate in the discussion but also could be considered highly engaged, as they knew about this event by being previously connected with the state-wide Parkinson's disease network. Thus, it is presumable that most of the participants with Parkinson's were not newly diagnosed and had sought some type of Parkinson's disease related services previously.

Because many of the people with Parkinson's disease stakeholders were already involved in support groups, this likely gave our results a more positive perspective than if we were able to include people with Parkinson's and caregivers that expressed dislike for support groups or those that did not find them beneficial. Participants relayed their experiences and perspectives in a group setting so that a community of Parkinson's stakeholders was represented, but as with all focus groups, the interaction could have potentially encouraged, hindered, or changed what participants shared. Focus group interviews, by their nature, may sway people's opinions before they have a chance to share. Often more out-going individuals may share their opinions and experiences first and may be more likely to enjoy groups if they have a more extroverted personality. Despite every focus group facilitator urging everyone in the group to participate, it is impossible to know whether some participants shared more or less than they would have in another scenario. When conducting focus group research, future investigators may consider a strategy to triangulate data shared by vocal focus group participants with the experiences of introverted and quieter participants. Potential strategies to give voice to reserved participants include providing each attendee at the focus group with a note card to provide any additional written comments or offering the option to participate in a separate one-to-one interview following the focus group.

The results of this are not meant to be generalized, as is the case with studies of this type and sample size. It is only meant to be interpreted for the targeted group of individuals, namely Parkinson's stakeholders in a rural and remote state. Many aspects that emerged from this study may or may not be present for those in urban locations or may differ in notable ways. For example, people with Parkinson's living in urban areas may also struggle with transportation, but in different ways as they may have access to public transportation. Issues may differ still given the specific rural, remote location where the study took place. The current study was in rural mountain terrain with harsh winters and unpredictable weather. Research on people with Parkinson's and caregivers living in other, less rugged areas, could provide additional insight into the benefits of and barriers to support group participation in other environments.

## Lessons Learned

Throughout this study, the researchers engaged in reflexivity as a necessary aspect of an interpretive phenomenological design. The researchers deemed the “patient” stakeholders as the experts about the disease experience. They collectively felt that to gain a perspective of experiencing Parkinson’s, one must converse with the person living with Parkinson’s disease and not just a caregiver, spouse, or other healthcare professional. Additionally, caregivers, professionals, and other stakeholders were seen as an integral part of the rural Parkinson’s community and had valuable insight and experiences with support groups. Ultimately, the researchers gained the perspective, through this study, that to improve or build upon existing resources for people with Parkinson’s, various types of community stakeholders with diverse backgrounds will be needed to truly incite change. A future aim of the researchers is to engage in participatory action research with these rural Parkinson’s stakeholders.

Living with chronic health conditions in rural locations negatively affects quality of life, and access to medical care (Coburn & Bolda, 1999). Thus, feasible and affordable methods of disease-management are necessary for people with PD (Lauckner & Hutchison, 2016). Support groups for individuals with Parkinson’s serve as crucial sources of information, as well as social and emotional support, particularly for those in rural areas, where access to other types of healthcare resources are scarce. These benefits cost little to nothing for individuals, further making them an ideal way to deal with some aspects of the disease in a rural location. Due to the considerable benefits cited, public domains (e.g., libraries, schools, and universities) could provide access to physical or online space for support groups. In addition, healthcare providers should help publicize support groups and encourage individuals with Parkinson’s to join them. Overall, information from this study can be used to improve support group access for people with Parkinson’s in rural areas. Future research exploring effective outreach methods to engage individuals with Parkinson’s could benefit groups that struggle to maintain sufficient participation as well as help create new models of support access in rural locations.

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We thank the Parkinson's stakeholders who shared their perspectives and experiences with us. Focus group moderators or co-moderators (in addition to the authors who served as moderators) were Rex Gantenbein, Christopher Herron, Beth Young Jones, Judith Powers, and Sandra Sundin. Transcriptionists included Katelynne Adams, Clarissa Petres, Brittney Arevalo, Allison Long, Bree Olson, Adele Riley, and Noel Schatz. We also thank the coordinators of the Wyoming Parkinson's Project, Sandra Sundin and Christopher Herron. The luncheon, travel, and accommodations for participants were paid for through a Patient Centered Outcomes Research Initiative (PCORI) Pipeline to Proposals: Tier III Grant. This PCORI award also paid student research assistants for their time transcribing.

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**Article Citation**

Bush, E. J., Singh, R. L., Hidecker, M. J. C., & Carrico, C. P. (2018). Parkinson's disease support groups in rural America: Barriers, resources, and opportunities. *The Qualitative Report*, 23(6), 1381-1400. Retrieved from <https://nsuworks.nova.edu/tqr/vol23/iss6/8>

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