

# Living with Parkinson's disease – perceptions of invisibility in a photovoice study

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## **ABSTRACT**

Based on previous community research, we prioritise the need to understand better how experiences and feelings of invisibility could be shaped by relational dynamics, interfacing with service provision, and social forces, with the overarching view of understanding better the experiences of participants living with Parkinson's disease. A photovoice methodology was employed. A discussion of one case study of Bindy and Volta leads to a better understanding of how strong spousal support can significantly alter how one individual experiences and defines living with Parkinson's.

**KEY WORDS** – Parkinson's, qualitative, spouse/family, photovoice.

## **Background**

Parkinson's disease is a degenerative neurological condition (World Health Organization 2006). There are over 65,000 individuals living with Parkinson's disease across Canada (Statistics Canada 2012, 2013). While these represent self-reported diagnoses, Parkinson Society Canada estimates that Parkinson's disease, in reality, affects over 100,000 Canadians (Parkinson Society Canada 2012). We can expect the number of people living with Parkinson's disease to increase alongside its ageing population, as it is a condition that tends to affect older age groups.

The experience of living with a neurological condition can be influenced by many contextual factors such as geography (*e.g.* rural/urban), level of health literacy (*e.g.* knowledge about Parkinson's), socio-economic status (*e.g.* ability to pay for additional supports), family support (*e.g.* if single and alone), as well as socio-demographic characteristics such as gender, age and ethnicity. One very important factor is that Canadians have a

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universal health system that is governed independently by each of the provinces, resulting in inconsistencies in health-care delivery across the country. A few recent Canadian studies have made an effort to study the Canadian experience of living with Parkinson's disease, including investigating the patient response to a Parkinson's diagnosis (Gofton and Jog 2008), patients' satisfaction with health services (Burns and Jensen 2012) and their 'everyday experience of living with and managing a neurological condition' (the LINC Study; Versnel *et al.* 2013). In addition, Roger and colleagues identified a need to conduct research with a local and regional focus, examining patients' perceptions of communication with informal and formal care providers (Penner and Roger 2012; Roger and Medved 2010; Roger, Medved and Mary-Quigley 2010; Roger and Penner 2012; Roger *et al.* 2014).

This paper discusses a single case regarding how one individual living with Parkinson's disease describes invisible and visible symptoms in the context of being part of a couple, and how this context shapes their social and life world.

### *Single case study*

In 2014, the authors hosted a half-day workshop for staff (social workers, managers, community stakeholders, people living with a range of chronic conditions including Parkinson's) from ten local organisations supporting those living with neurological conditions. Through the participation of community organisations, 'invisibility' and 'advocacy and education' arose as the main priorities for local community organisations. More specifically, participants living with chronic conditions described how others (including family and friends) lacked an understanding of how their symptoms impacted their daily life in general, given that their symptoms were primarily invisible: living with pain, mental fatigue, communication difficulties, imposed planning requirements or resulting family role changes. This sense of 'invisibility' became key in furthering our research. Previous research seems to corroborate the experiences of the workshop's participants. Invisible symptoms, including pain, fatigue, depression and anxiety, commonly accompany neurological conditions (Tsang and Macdonell 2011) including Parkinson's disease (Nolden, Tartavouille and Porch 2014). Furthermore, these invisible symptoms have been found to be more distressing for patients than visible symptoms (speech difficulties, problems with balance and the use of assistive devices), underscoring the significance of the subjective experience of patients (White, White and Russell 2008). Invisible symptoms more easily lead to not receiving the support and recognition that patients require. Thorne *et al.* (2004) conducted a study that explored issues around health-care communications and found that

some patients experienced the pre-diagnostic phase as difficult, when there was a risk that health professionals dismiss their reports of symptoms.

Our 2014 workshop participants similarly reported that the general lack of awareness from their community neighbours, health-care professionals and family in their daily lives greatly impacted their social relationships, employment opportunities/accommodation as well as access to the community services (*i.e.* transportation, home care). These impacts left many feeling socially isolated, frustrated, ignored and/or stigmatised when they said others did not understand or acknowledge the many symptoms and associated consequences they dealt with on a daily basis.

In addition, participants felt this lack of awareness of most neurological conditions extended to the health-care system, leading to incorrect and prolonged diagnoses, as well as other barriers to available treatment and care. For example, while technology and tests are heavily relied upon today, they make both patients and clinicians vulnerable to quick answers. It requires a leap of faith by a professional to stay with a patient's experience in order to provide the best possible symptom management, otherwise clinicians may inadvertently exacerbate the negative experiences of their patients with the health-care system.

A lack of awareness of Parkinson's disease left some participants in this workshop feeling that their symptoms were invisible, and indeed their experience of being unwell, in a health system meant to care for them. Furthermore, in our 2014 workshop, participants unanimously expressed concern over the difficulty associated with navigating through the health-care system. Self-advocacy was difficult for patients whose symptoms could not be seen easily, and who felt they were often forced to manoeuvre through the intricacies of the health-care system in an effort to find appropriate services, at a time when they are overwhelmed by their diagnosis as well as the symptoms of their long-term condition. In this context, having a spouse or a primary care-giver became one key element in the wellbeing of the individuals living with Parkinson's disease. We came to recognise that those who were best able to navigate the changes associated with Parkinson's disease were those who had supports (a central in-house care-giver or a spouse/partner) accompanying them through their journey or had tapped into a one-stop health-care centre that served many of their needs.

### *Research objectives*

Through the work in the community described above, we received a grant to investigate further the experiences related to invisibility. The funder felt strongly that this focus was of value. We prioritised the need to understand better how experiences related to invisibility and invisible symptoms could

be shaped by relational dynamics and social forces, with the overarching view of better understanding and providing recommendations on the experiences of participants within the health-care environment. Consequently, upon receiving this funding, the most recent study (upon which this paper is based) examined the ways in which participants experienced their invisible symptoms either in their personal lives with family or in their communities. Because other chronic conditions can hold similar experiences, as our workshop experience demonstrated, this paper contributes a new focus to existing research. This paper utilises photovoice data to explore related issues.

## **Methods**

### *Photovoice design*

This study employed qualitative methodology blending photography with open-ended interviews yielding personal reflections surrounding those pictures. This represents an approach adapted from Carolyn C. Wang and Mary Ann Burris's photovoice methodology, which was first presented in the mid-1990s (Wang 1999; Wang and Burris 1997; Wang *et al.* 1998). Since its development, photovoice has been used in the investigation of many case studies with a range of research topics and geographical locations to document and address realities facing individuals and communities (Catalani and Minkler 2010).

### *Participant recruitment*

An ethics protocol was submitted and approved by the appropriate Ethics Review Committee. A purposeful sampling strategy was utilised to recruit participants for this study. In order to locate participants, targeted recruitment occurred predominantly through organisations that work specifically with people living with Parkinson's disease and their carers living in the community in a large Prairie centre in Canada, thus building on existing partnerships with national and local organisations, such as the local and national Parkinson's Society, the Neurological Health Charities of Canada and the locally renowned Movement Disorder Program. A poster outlining the study and word-of-mouth were used to solicit participants.

### *Data collection*

All participants attended an initial presentation at a time and location of their choice. An overview of photovoice was provided, as well as how it

would be used in this study. To engage participants and ensure their full understanding of the presentation's material, they were subsequently engaged in discussions of how they could take pictures of people, places or objects to demonstrate feelings of invisibility when interacting with their family, community or care professionals. They were provided with a disposable camera, or were allowed to use their own personal devices if they were password protected. They were instructed on camera use and asked to contact the lead researcher when they had finished taking pictures or within three months' time. Three couples were recruited in total. Two couples are not included in this study due to incomplete interviews for a variety of reasons.

Therefore this paper focuses on the remaining couple, whom we shall call Bindy (the wife) and Volta (the man living with Parkinson's disease), married for over 30 years and who have grown children. They are retired and have been living with the Parkinson's of Volta for over ten years. This was an unexpected and unusual case in that the strengths of their history together and good communication in their relationship allowed them to navigate the changes associated with Parkinson's disease in an expert way. Bindy and Volta requested being interviewed together rather than separately, and this elicited common and divergent stories based on the photographs and themes that emerged. They were asked to talk about their experiences using as many photographs as they desired. Bindy and Volta created a logbook which was essential in providing a guide during the interview for why certain photographs were taken, but it also allowed us (the research team) to understand the data in a more contextual way. The participants discussed in detail the photographs they took, as well as their stories of invisibility, past and present, as they related them to their journey. In total, the interview was roughly two hours long.

### *Data analysis*

The audio recordings of the interviews, in tandem with the photographs, were transcribed and the members of the research team independently checked the transcriptions for accuracy. Both sets of interviews and the photographs were analysed together – line by line by the lead investigator and two other members of the research team. Data generated through the interviews was subjected to open coding (Braun and Clarke 2013) and aggregated into meaningful categories by the research team. Refinement of category structure and assignment of data to categories was done in collaboration with members of the team, who independently verified the development of emerging categories and analysis, and provided input to improve the reliability of the results. The research team engaged in

consensus building around the coded and categorised data, improving the validity of the findings. Where consensus was not reached, discrepancies have been noted and included as part of the findings.

Rigour was sought in ways established for content analysis and in qualitative research (Braun and Clarke 2013). An audit trail of the analysis, including memos along the way, was maintained throughout the analytic process and reviewed by the research team in order to compare emerging categories and their relevant meaning. Because of the interdisciplinary nature of the team and the resulting diversity in investigator backgrounds and professional training, they brought different perspectives to the data analysis, thereby minimising the chance of bias from a single perspective or expertise base. Attention was paid to discrepant data at several stages of the analysis by proposing alternative explanations or coming to an understanding of existing themes in the context of the literature. Key objectives of the study were taken into account throughout the data analysis, and surprising new themes or unexpected findings were discussed and presented.

## Findings

Five inter-related themes emerged from the interview data associated with the sequence of photographs taken by Bindy and Volta: (a) medication and time; (b) household daily living; (c) physical activities; (d) mental activities; and (e) community activities. Volta had taken all the photographs himself and directed their order and purpose, but Bindy had to record in the logbook what Volta felt was important about each picture, since his handwriting was not only very slow, but also small and illegible. In reviewing the pictures and the logbook, we realised that their pictures took on an organic sequence, which we were able to depict in a conceptual model, shown in [Figure 1](#). This model depicts the different levels of Bindy and Volta's environments based on the content and flow of their photographs and the logbook sequence. This reflects that the order of the photographs as taken by Volta mirrors his hierarchy of priorities – as the themes move from inside the most inner circle (the highest most pressing needs) to the periphery (less pressing needs). As we will describe, shifting between invisibility and visibility is apparent in each of the themes.

[Figure 1](#) illustrates the themes as they emerged in the data, moving from within with the more personal themes to the outside with more social, public-related themes. These will be discussed in this paper. Volta (V) represents the full circle from within to the perimeter with all his experiences; and Bindy (B) is present as the arrow by cutting through all of Volta's experiences.

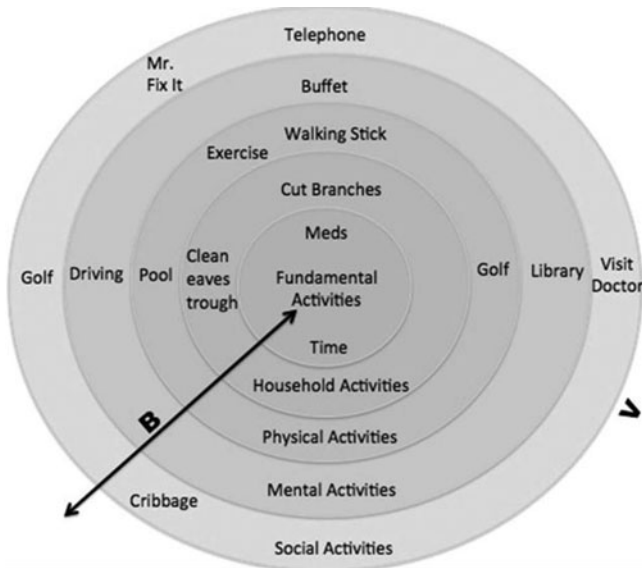


Figure 1. THEMES.

Notes: V: Volta. B: Bindy.

### *Medication and time*

At the centre of the conceptual model (Figure 1), and of highest importance to Bindy and Volta, is the theme of medication. Both identified the importance that Volta be properly medicated and that this needs to happen on time.

When elaborating on the photograph in Figure 2, Volta said 'I didn't do anything without assuring that I had my meds with me, and [was] prepared to take them'. In fact, Volta used different aids to ensure he took his medication on time. In our interview, he also identified the use of his alarm watch, stating 'it lets me have some freedom to go about my daily chores or daily activities and not have to worry about looking at the clock all the time to see if it's going to be medication time'. In addition, he showed a travel case that allowed him to have the appropriate doses of his medication while he was away. In addition, though the medication was prescribed for Volta, as his partner and primary care-giver, Bindy took an active role in supporting Volta taking his medication on time. Volta explained '[s]he reminds me ... I get most of the credit', 'she notices if I'm being interrupted'. In a sense, since Bindy was 'always there', she acted as a safety net or second alarm for Volta. Together, with the aids and Bindy's support, Volta had the ability to sustain an ongoing routine of proper medication that



Figure 2. Volta's photograph: Medicine: 'it's our whole life'.

allowed for the rest of his day to unfold more naturally. He explained his ongoing routine in the following quote:

[N]o matter where we go, we check the time that we're going to be away and I have a travel ... case. I would put in a dosage of medicine, so that ... when my alarm goes off I got my meds there to consume.

While taking medications appears to be a micro-level activity in Bindy and Volta's life, it is apparent in comments such as 'It's our whole life', that Volta's medication was an integral part of his disease management that would be present and affect many areas of their lives. On the one hand, they were both bound to the repetitive routine of organising and administering the medication; and yet, with the assistance of his watch and travel case, Bindy and Volta were freed from some of the symptoms of Parkinson's. As a result, medication became integrated into all of Bindy and Volta's activities and attitudes, and simultaneously became the fundamental reason why they were able to engage with life beyond Parkinson's. Bindy explains that once the medication was dealt with, they could focus on other things.

And why it is a necessity is before he had the watch, you're looking at the clock constantly. Oh what times is it, oh it's only 11:15 and it's precisely important that you do your meds exactly the same time to the minute because your brain puts the



dopamine in your body at the right time all the time. So that's what we're trying to fake you see. So ... it's 11:30, not 11:45, sometimes you sway but really really strive to keep it exact. And the watch eliminates all of that. You can be doing something and you hear your beep 'oh!' cutting the grass and then he comes in and takes his meds. So it relieves, it frees you. It frees you ... [T]he meds thing. That's his life. You do that once a week, you set up all your meds for the whole week and then you can put it to bed type of thing.

The narrative around medication management highlighted the interdependence of this couple. Bindy vacillated between using the pronouns 'you', 'he' and 'we'. There was a merging of the two as a couple, and at times, it was unclear whom the medications were for. Bindy and Volta shared this significant activity – an activity that had become central in their lives but was hidden from the view of others. For example, medication kept Volta's symptoms under control (and more invisible).

Interestingly, the fact that others did not recognise Volta's symptoms was not an issue for Volta or Bindy as both worked hard to keep the symptoms out of the view of others. Here, we begin to see their ongoing and daily practice of shifting between invisibility and visibility of symptoms through medication and timeliness.

### *Household daily living*

Once medicated, though not all symptoms were alleviated, Bindy and Volta were able to focus a little more on daily living. According to the order of their photographs and the logbook as well as the interview, the home then became the next space through which they interacted (Figure 3). In their narratives, their home appeared to act as a place of refuge where Volta was comfortable enough to make decisions in his own time, unlike the fast-paced or unfamiliar environment of a dentist's office, selecting food at a buffet or picking out a book at the library (all examples given by him throughout the interview). Even more, it appeared that their home was a place which they took great pride in doing 'huge projects' over time: 'I like doing projects. Love it'. Bindy further paints a picture of their lives, saying:

[T]hat's basically the way we've dealt with each other all our lives. If I say ... 'this is broken'. It's fixed in the next five seconds. Always has been like that. And if he says, 'my shirt is ripped, you know, the button fell off'. The button is on in the next three minutes (chuckle). That's the way we operate.

From this viewpoint, we begin to see the effects on Volta of the progression of his Parkinson's disease as he listed off different household tasks that he used to be able to complete with ease, but which were now hampered by his condition. While cleaning eaves troughs on the sun porch or climbing



Figure 3. Volta's photograph: 'If it was broken – I fixed it'.

trees to cut branches were things that Volta once enjoyed or identified as important, he was clearly now in a space to consider the risks and make a decision on how to proceed based on his Parkinson's disease. Volta explained: '[Y]ou have to look at a job and assess it. And if it's dangerous, then based on my capabilities, before and after, I just wouldn't do it'. Bindy was always encouraging him to put his safety first regardless of the importance of the tasks, even though this meant losing an important shared activity. In this way, their home represented a space where Volta's Parkinson's disease was visible on a daily basis, and consequently, Bindy and Volta were able to find ways of completing important tasks that considered Volta's abilities.

I don't want him falling out of the tree and breaking his neck thank you very much. So we have phoned the fellow but he didn't come but it's no big deal, we'll have it done at a later time. But it's important. (Bindy)

In addition, after considering Volta's abilities and limitations, they also gave examples where Bindy offered to complete a particular task, or Volta invented his own assistive devices. For example, Bindy and Volta describe the latter scenario:

Bindy: That's just an invention...

Volta: It's a stick with a brush on the top and then just go along, I got ... these covering on the ... eaves trough ... It was out of necessity.

Their clear pride and joy at developing an alternative tool through which Volta could do household chores was evident. In the privacy of their home, they were more comfortable allowing for his limitations to emerge.

They both managed and communicated about how to complete daily tasks they both had done together for years. This was the only realm in which being 'visible' with symptoms and Parkinson's felt so comfortable.

### *Physical activities*

As a young man Volta played many sports, such as hockey, baseball and football. Yet, even when faced with Parkinson's disease, he maintained his zest for supporting his physical wellbeing. He stated, 'Exercise is a big part of your daily living. You have to do some exercises, otherwise, you stiffen up'. Photographs and stories revealed how prioritising exercise in their schedule enabled Volta to continue engaging in an active lifestyle in the face of his condition, but that there were challenges.

[H]e's good, like, oh ya, like it's, he needs very little prompting. But ... if you get out of schedule, for example, there are some mornings he can't. There's Parkinson's [appointments] one morning, weight lifting the next, Parkinson's the next. But we have an activity on certain mornings, you miss that activity, you know, so therefore you know, you have to reschedule your exercise sometimes and then it'll get done. (Bindy)

Yet, while similar to household activities, his acceptance of his disabilities in public meant he had to manage their visibility. More specifically, he mentioned that he modified the types of activity he engaged in, substituting previously high-impact sports for curling, weights, golf and programmed exercises. For example, he also managed to craft his own assistive device, by carving a 'Diamond Willow walking stick' that would help him 'pull along with one side to the other' when he walked and give him balance in 'areas that it's not quite that level'. This was a real achievement for him as he felt he could be in public without being seen to have Parkinson's disease. Together with Bindy's support, he was able to adjust the intensity and regularity of activities he wanted to continue, as depicted in the following quote:

[W]hat I can intercede was you miss the bonding that you golf with your buddies, that was big time fun. Where you go with your buddies to golf. Whereas now, he ... I just, he just golfs with me ... He wouldn't be capable of doing 18 holes anymore and ... he's not as comfortable with his calibre of game.

This was a big change for both of them – Bindy became Volta's primary golf partner, but again, this allowed him to continue to engage in a favourite activity without someone watching over his symptoms – she stepped in to maintain his activity level and he could still go golfing. Publicly, Volta remained by all appearances an active and happy golf player where symptoms and health issues were kept out of sight of others. Shifting between

invisibility and visibility was the norm, and Bindy was central to that outcome.

### *Mental activities*

The fourth phase of Bindy and Volta's photographs and logbook (*see Figure 1*) included issues related to mental or cognitive activities. In addition to physical activities, Volta regularly faced decisions, such as picking books at the library, choosing food at buffets and driving. As with many older-aged citizens, Volta's cognitive speed may have been the result of a combination of elements beyond his Parkinson's disease, such as age or his diminished vision in one eye. Volta noticed that he had diminished cognitive functioning that made it difficult for him to process information at a speed that is typically demanded in today's society. 'I have trouble making up my mind', he says. His wife reinforced this in the following story:

He's just not fast enough. Just not fast enough. You don't want to be behind Volta at a buffet table. No. He's just not fast enough. And of course you're co-ordinating your plate ... You don't want to spill. You want to be extra careful.

She states that she either helped him put food on his plate 'in a way that no one else would notice', or she would fill his plate and bring it to him. In other cases, as at the library, Bindy was able to coach Volta through decisions about which books to take out – she became his right hand and set of eyes, almost managing his every step. Bindy confidently explained how she always knew what Volta wanted: 'I pretty well know what he's going to like or not like'. Once again, as his partner, Bindy's knowledge of Volta's limitations allowed her to anticipate areas that would be challenging for him and manage, cover up or assist him in those activities. For instance:

It's when you look at all these books, he's done ... He's at the end of his book and we need to go to the library, and I help search out his authors that he likes. 'Which ones do you have on your list' and I help because it's just overwhelming to deal with all those books ... He'll get focused on just one and you know you need to branch out, we all do. And I'll say, 'why don't you try this one' and he'll ... I'll get him to sit down at the table and I start bringing him books and he reads. (Bindy)

In instances where Volta's actions had little to no effect on others, Bindy's support focused on Volta's decision-making processes. However, when it came to elements that may have impacted others, her support seemed to result in her controlling the situation. According to Bindy, this monitoring resulted in her filling in the gaps where community members were unaware of Volta's Parkinson's disease. She was proud in these moments and said she felt needed, as well as saying she had always been the more active and directive of the two.

A lot of them don't even know he has Parkinson's. And the reason for it is I do a lot of cover up so in other words ... If I'm before him in a buffet table, I'm here – 'You have this, you have this, this and this, and you're done'. So a lot of women would do that for their husbands anyways. So it's ... people don't realise. (Bindy)

Interestingly, while it was the invisibility of Volta's symptoms that made it difficult for him to participate in activities, like filling his plate at the buffet, Bindy seemed to be preserving this secret happily and regularly. Shifting between invisibility and visibility again was beneficial to Bindy and administered in great part by her assistance. It was apparent that she was quite aware of her role when she stated, 'I do a lot of cover up'.

### *Social activities: telephone, cribbage, curling*

In the remaining photographs, Bindy and Volta described the significance of their social activities in the community, and some of the difficulties Volta now faced in social interactions. Some of these difficulties were attributed to gender differences (*e.g.* when Volta's golf-mates were less inclined to socialise with him this was viewed as what 'men do'). Consistent with Volta's Parkinson's disease, this influenced his ability to engage in fast-paced social environments. According to Bindy, 'he can't formulate his thoughts fast enough. So ... he might be able to answer but we're already on to the next topic'. Volta supports this statement by saying, 'I can't keep up with the conversation. I don't have much to add to it. And ... I sort of stand back a little bit and let the more vocal ones carry on'.

Volta recounted his experience speaking on the phone: 'I don't like answering the phone because I don't speak loud enough [or] clear enough to communicate to the person on the other end of the phone'. Though the telephone represents a household item, it connects Bindy and Volta to the community in important ways and yet Volta was not comfortable using the phone, increasing his retreat from social interactions. Volta also shared his difficulties with telephone banking with us, which he said was more difficult than speaking with family and friends.

As mentioned earlier, many individuals in the community were unaware of Volta's Parkinson's disease; and yet, it appears that when his condition was disclosed, he seemed to become more comfortable. For example, at the curling rink, Volta befriended a group of men who 'tuned-in' to his pace, allowing Volta to contribute to the conversation, such as the 'different sporting events that had taken place' (Figure 4). This was an invaluable addition to his social life. In addition, Volta really enjoyed playing cribbage with a group of friends, where he was able to take pride in his superior performance, a long-standing skill he was proud of, as well as passing on guidance to a fellow member living with Parkinson's disease about what she could expect



Figure 4. Volta's photograph: The curling rink: 'tuning in to my pace'.

from her condition. He explained, 'If I can have a solution. I'd pass it on to them [and this makes me happy]'. Bindy indicated the significance of a similar kind of sharing at their support group sessions, stating: 'Very helpful ... [T]here's always somebody in the group that has a solution'.

Indeed, awareness and acceptance of Volta's condition appeared to do wonders in creating a positive and welcoming environment for Volta. Nevertheless, there continued to be parts of Volta's life that were less accommodating to Volta's needs, where Bindy continued to play an important role managing these social interactions and keeping his Parkinson's invisible – 'out of the view of others'. Most notably, Volta faced a great change in his life when he was no longer able to live up to others' expectations of being 'Mr. Fix It' for everybody. In this instance, Bindy was able to buffer the situation for him by confronting those 'who were [continuously] relying on him to "come and fix my light", "come and fix this"'. She said: 'It comes through me. Only I deal with that – "No he can't do it, yes he can do it"'

Likewise, Bindy became a protector for Volta in the health-care arena as well, and she anticipated the limitations of care providers to ensure Volta was not lost in the system. When phone calls to medical receptionists were necessary, she was the communicator. Furthermore, Bindy would talk directly to the receptionist to ensure she was in on the appointment. Bindy was well aware that care providers were sometimes insensitive to Volta's invisible cognitive symptoms, so she compensated and became his listener. During visits with health-care professionals, Bindy would join Volta to help him process the information given by the doctors when they required rapid decision-making.

I said to the receptionist, I need to be in on the consultation because it's a whole lot of information like ... what this is gonna cost us, what they're gonna do, how this would happen, this is what you need to do and he ... he could bring it home and think about it, but you need to do it, make your decision quickly and then...

Additionally, in the doctor's office, because speed is often emphasised over patient involvement, Bindy ensured Volta's needs were met. She states, '[S]ome questions that the doctor asks ... he's looking at me for an answer *versus* for Volta'. Not only was Volta dependent on her in this role, but it is evident in this quote that the physician was dependent on her as well. When the doctor turned to speak to Bindy, Volta disappeared. However, Bindy worked to prevent Volta from disappearing completely and ensured that he received his medical treatment.

Interestingly, Bindy's influence seemed to cut across all activities and environments in Volta's life, to act as his supporter, protector and partner. Bindy has grown to learn all of Volta's likes and dislikes, yet she herself must be reminded by her children to allow Volta to think, decide and speak for himself at his own pace. For instance, Bindy explained how her children created opportunities for their father to speak at his own pace:

[A]s you can see, I talk a lot, I take over. They make sure, they correct me on that. They'll say, 'well what do you think about that Dad?' If I start answering, they'll say 'well what do you think Dad'. And that's when I say, 'well I already know what he thinks I can tell you that'.

## **Discussion**

This case study used a photovoice methodology to explore one couple's experience of Parkinson's. We live in a culture that predominantly favours hard work and independence, and in particular, the ability to self-advocate in the face of adversity. Unfortunately, the limitations that Parkinson's disease imposes on individuals interfere with their ability to meet these social norms and standards. One key issue in the experience of this disease is that symptoms are not always visible and, in fact, multiple experiences compound to reinforce their invisibility. Bindy and Volta's narrative beautifully illustrates how mutual acceptance of this disease was managed, monitored and 'lived' to be invisible, as well as how it provided purpose and structure to their relationship and daily lives. The experience of also feeling invalidated, not supported or recognised, due to these invisible symptoms, is key to this couple managing the public stigma they did and might face further in the future. However, the case also illustrates that family members may be invested in minimising symptoms or managing them to the extent of normalising them – protecting their own lack of acceptance or



denial in the face of 'looking normal'. Certainly, a long history together and a fluid relational intersubjectivity could complicate while also strengthening any couple's best strategies. Bindy and Volta had a strong partnership before the disease entered their lives, and they were able to adjust their roles within that partnership, partly in an effort to protect themselves from others who they felt would not be accepting of the changes due to Parkinson's disease. This protection did lead to sustaining invisibility of the symptoms, and thus of the experience of living with Parkinson's, as this paper has shown. Bindy was quite outspoken about the ways in which she and Volta felt misunderstood by others, and within the health-care system, but ironically, she also worked hard to manufacture invisibility of Volta's symptoms and her own experience. This at times resulted in Volta's experience disappearing in the face of her management. This effort or management has been described in this paper as 'shifting between invisibility and visibility', and Bindy and Volta were a high-functioning and fairly successful couple in this regard. In sharing their daily stories with us, Bindy and Volta allowed us to have an in-depth look at their experience and how some realities were manufactured as 'for their eyes only'. This could at times include their friends, but rarely the general public.

Specific to people living with Parkinson's disease, their acceptance of the long-term condition was associated with a positive reinterpretation of their situations (Baker 1998). In this case, we see Bindy as being very engaged and accepting of Volta's limitations; she responded to his condition by moving in rather than disengaging. Volta did not seem to mind this, as he said he was familiar with her style. They described a marriage that has always been a partnership, and they were partners in this new venture as well. Bindy's active engagement was indicative of her acceptance as well as her desire to maintain a sense of normalcy for the eyes of the public, but as she became more involved in Volta's adjustment, she also found a purpose in this role of hiding from others what is unseemly or hard to accept about Parkinson's disease.

As seen in our current study, Bindy and Volta seemed to work together and support each other, which in turn, contributed to mutual increases in acceptance of his Parkinson's disease. In fact, 'working around' Volta's Parkinson's disease became another project that they did together; they pragmatically assessed Volta's ongoing decline and they both adjusted their behavior in ways that allowed them both to carry on life as fully as possible. Because Bindy embraced her role in Volta's ongoing adaption required by his condition, he did not have to fear that he was a burden, and because he accepted his limitations, she did not have to face the difficulties that his avoidance would cause her – they moved together in



acceptance. However, this also shaped and defined a kind of invisibility, where others could not and did not see what is really going on, and through which even Bindy and Volta could become entangled in their own story and narrative of normalcy.

An essential aspect of accepting illness (or in this case a long-term condition) is witnessing it, as compared with denying its existence or significance. Bindy was a good witness, tuned into all of 'its' presence in their lives, including the less-visible cognitive symptoms (cognitive slowing, difficulty with choices, difficulty following conversation). Although she accepted the long-term condition as real and present, she hid its presence from the outside world by jumping in to compensate for Volta's losses. This became key to shifting between invisibility (managing the symptoms from the eyes of the public but perhaps also the health-care system) and visibility (being seen as less normal but receiving support and recognition that could be desirable). Bindy had to accept the Parkinson's herself if she was to simultaneously hide it from others. In this way, she preserved Volta's image as a man of health and full-functional ability – who he has been – for the rest of the world. This benefited her own image of herself as a good partner – as it was clear throughout their interview that she personally valued that image.

This care-giving role, where the care-giver maintains the selfhood of her ill partner, has been observed in previous studies (Karner and Bobbitt-Zeher 2005; Penner and Rogers 2012). While we were not exploring the gendered aspects of this relationship, it is clear that Bindy was assuming a more traditional female care-giving role. Bindy worked to make Volta's deficits as invisible as possible to those who are not close. He accepted a relatively passive role in this venture, so that it was possible for Bindy to cover for him. In this way, she may also have been maintaining her own identity because their 'selves' were intertwined after years of being together. This need to 'cover' has been found in Hermann's (2013) research in which she followed two Parkinson's disease support groups over a two-year period and found that her participants experienced a changing self, which resulted in stigma and feelings of isolation. Many of the participants in the 2014 workshop also reported that they would deliberately hide their symptoms. In the case of Bindy and Volta, Bindy did this work for Volta: she covered for him, which released him from this stress. Although Bindy and Volta were able to accept the condition as a long-term one, they did not assume that others would. The participants in Hermann's study described the sense of isolation that they felt when they had to hide their truth. In Volta's case, although he was becoming more isolated from some of his friends, Bindy moved in as Volta withdrew from former relationships due to physical and cognitive limitations. In this way, their strong marital

relationship provided shelter and softened the losses he was experiencing. This was done through a constant shift between invisibility and visibility of their daily lived experience with Parkinson's disease.

Finally, the value of asking Volta to take pictures of his experience became not only a treasured activity between the two of them, it deepened our discussion of the research question; the photographs allowed us to enter into more detail about their experience than perhaps the discussion would have without the photographs. The photographs themselves also become a kind of stand alone data-set, a happy visual reminder and encounter for the interview process where a smile played on Volta's lips recalling an incident he saw in a photograph, or they set off a visual narrative which led to a deep reflection of a strength he had had previously. The photographs deepened and strengthened our understanding of how Volta sees his life with Parkinson's.

### **Implications for health-care professionals**

This single case study has shown that individuals may strive to find a balance between invisibility (lack of support and understanding of invisible symptoms) and visibility in their personal lives, in a way that promotes a language and narrative of normalcy. 'Normal in the eyes of others' is positioned in counterpoint to 'abnormal and for our eyes only'. This dance pertains then also to their successful entry into the health-care system. Full acceptance of the long-term nature of the condition is very important with regards to obtaining good medical care. If a couple does not clearly acknowledge the limitations that the disease imposes upon an individual's communication processes, this can result in insufficient support.

Patients and providers need to see and acknowledge symptoms that exist in the shadows (or hidden in the context of a relationship), so that diagnoses are not delayed and effective and timely treatment and care can be provided. Through this process, patients should not be expected to diagnose themselves or know what they are experiencing in medical terms, rather together a language can be found that accurately describes the daily lived experience of the patient in a way that recognises its 'truth' and 'truth value' outside a medical model of care. The medical model of care, which places emphasis on diagnosis and treatment, dominates the health-care system and can at times ignore or devalue such stories. As this system becomes increasingly impacted by financial and time pressures, and as the reliance on technology and medical tests increases, those who suffer with invisible symptoms may be more vulnerable to being ignored or discredited.

Research has provided some evidence regarding the vulnerability of patients. For example, a study conducted in 2001 found that physicians often interrupt patients before they have finished speaking (Rhoades *et al.* 2001). This tendency to interrupt may be a result of time pressure, but also may be related to other factors, such as impatience or lack of empathy. Because people with Parkinson's disease have communication difficulties and speak slowly, this leaves them particularly vulnerable to inadequate medical encounters. Compounding this is the fact that 'masked faces' is a common symptom of Parkinson's disease and can interfere with the ability to communicate with physicians. A study by Tickle-Degnen and Lyons (2004) found that physicians, especially new physicians, tended to see a lack of facial expression as an outward expression of their patient's character, rather than a neurologic symptom. The doctors in this study misperceived increased masking as neuroticism (Tickle-Degnen and Lyons 2004). Bindy and Volta knew he was vulnerable with regards to having his concerns overlooked because they did not engage in denial or minimise his vulnerabilities. Other less highly functioning couples may not be as capable.

We hope that this paper has revealed more about the management of symptoms and a person's experience of invisibility. Couples have 'shifted between invisibility and visibility' for so long that a highly successful and intricate reality has shaped their daily lived experience of living with Parkinson's. Key implications have emerged for health-care providers:

1. Determine through assessments whether a couple, care-giver or support person is aware of the symptoms and knowingly managing them, or is in denial.
2. To be mindful of listening to and believing patients when they speak about invisible symptoms. Fatigue and pain are difficult symptoms to recognise, and malingering is not the norm.
3. Provide assistance regarding communicating about symptoms, for people who may be in denial or not aware of symptoms, in particular regarding their access to and entry into the health-care system.
4. Take into account verbal communication barriers and facial expressions in tandem with health-care time pressures and moving too quickly for the patient.

### *Limitations*

Although a small number of participants does not influence the quality of participation, according to the review of photovoice literature by Catalani and Minkler (2010), there is a direct relationship between the number of

participants and influencing action. Understandably, as this represents an initial exploratory study, the findings are insufficient to address current realities or engage policy makers, a known challenge to this method (Nykiforuk, Vallianatos and Nieuwendyk 2011). However, it does act as a foundation for future researchers to use photovoice as tool to continue developing future education and advocacy efforts in support of this population.

## Conclusion

High-functioning marital couples, such as the one featured in this paper, teach us a great deal about how partners can cope and maintain meaning in life when one of them is faced with a life-altering and long-term health condition. This togetherness also meant that Volta's experience of invisibility in other social places was managed together. Bindy and Volta did this well because they were together; they felt they were much stronger than if they were alone. This tells us a lot about the power of connection in managing the sense of visibility, but also suggests that if marriages are conflictual or if people are widowed or single, these individuals may be at particular risk of being less visible or disappearing in the system. These people may have a tendency to become more isolated in their experience of Parkinson's and more vulnerable to not having their medical or emotional needs met. This suggests an important area of future research with regards to living alone with a long-term condition such as Parkinson's that imposes limitations on personal functioning, that is poorly understood by others and that has a constellation of life-altering symptoms that others cannot 'see'.

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