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Impact of deep brain stimulation on people with Parkinson's disease: A mixed methods feasibility study exploring lifespace and community outcomes

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Abstract

Background: Deep brain stimulation is a surgical treatment for Parkinson's disease. Its impacts on motor symptoms are widely reported; however, little is known about the broader impact of deep brain stimulation on the community lives of people with Parkinson's disease. Lifespace is a measure of lived community mobility, providing an indication of community access and participation.

Aims: This pilot study explored the feasibility of remotely monitoring the qualitative and quantitative community outcomes related to deep brain stimulation.

Methods: A longitudinal mixed methods study with a convergent design was undertaken exploring the lifespace, quality of life, life satisfaction and lived experiences of people with Parkinson's disease before and after deep brain stimulation. Data were collected through questionnaires, semi-structured interviews and a smartphone-based application which collected geolocation data.

Results: Quantitative and qualitative data from eight participants living with Parkinson's disease were analysed and integrated. At baseline, participants had a median age of 68 years and a median Hoehn and Yahr score of 2. Measuring a range of community-based outcomes indicated different change trajectories for individuals across outcomes. Key content areas were developed from the qualitative data: participation in occupations and travel and home. This study indicates the potential value of including geolocation data-based lifespace collection in metropolitan and regional areas.

Conclusions: Monitoring lifespace in conjunction with subjective measures provides insights into the complex and individually varied experiences. Further research could explore the impacts of deep brain stimulation on occupations and community participation to gain a deeper understanding of the related needs and support clinical approaches.

Keywords
Feasibility, lifespace, lived experience, occupations

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Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease in the world (Access Economics, 2015). It is progressive and characterised by motor and non-motor symptoms (Collins, Lehmann, & Patil, 2010). Tremor, bradykinesia, rigidity and postural instability are the cardinal motor symptoms and non-motor symptoms include

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disturbances of mood, cognition and sleep (Haahr, Kirkevold, Hall, & Østergaard, 2010; Okun, 2012).

Pharmacological treatment is common for PD. However, while often effective initially, medication-related complications commonly develop after a few years (Okun, 2012). This includes periods of on–off fluctuations, dyskinesia and involuntary movements (Haahr, Kirkevold, Hall, & Østergaard, 2011). In the last decade, deep brain stimulation (DBS) has emerged as an effective surgical treatment for movement disorders such as PD (Collins et al., 2010). DBS involves implanting an electrode in a targeted site in the brain, and a stimulator or pacemaker in the chest. Electrical impulses sent from the stimulator through the electrode act on targeted circuitry within the brain and regulate activity, reducing motor symptoms in PD (Perestelo-Perez et al., 2014).

Research into the impacts of DBS has traditionally centred on symptom-focused measures, and clinical trials have reported significant improvements in motor function and health-related quality of life (Deuschl et al., 2006; Perestelo-Perez et al., 2014; Schüpbach et al., 2007). Substantial symptom improvement in tremor, gait speed, rigidity and bradykinesia have been shown in clinical trials along with reduction in requirement for dopaminergic medication (Mansouri et al., 2018). However, this may not provide an adequate assessment of treatment outcomes (Kubu & Ford, 2012; Liddle, Phillips, Gustafsson, & Silburn, 2018). Despite symptom improvements, there is emerging discussion about the potential complexity of outcomes, with some suggestion that symptom improvements do not necessarily translate into improved life satisfaction and participation (Schupbach et al., 2006). A descriptive phenomenological study indicated that people with Parkinson's undergoing DBS understood their experiences with Parkinson's and DBS through the lens of occupational experiences and changes (Liddle et al., 2018).

In a longitudinal interview study, participants described the substantial changes experienced in the first year after DBS. These included the stimulation adjustment process, development of new symptoms and the impact of changes, both positive and negative, on relationships and roles (Haahr et al., 2010). A more recent exploration of DBS experiences of people with Parkinson's indicated that particular education, clinical and support needs were experienced at different times (Liddle, Beazley, Gustafsson, & Silburn, 2019). Timely clinical support may be required to support adjustment and participation in meaningful occupations (Liddle et al., 2018, 2019). The recovery period after DBS is a key transition time requiring a focus on occupational participation, health and wellbeing outcomes.

Emerging research is now exploring the lived experience of PD and DBS, and the broader impacts of symptom improvements on participation within the community (Haahr et al., 2011, 2010; Liddle et al., 2018). Participation within the community may be indicated by lifespace. Lifespace is the geographic area in which individuals move and carry out their daily lives, and is a quantitative measure that indicates patterns and extent of community access (Daneault et al., 2014; Liddle et al., 2014).

In the past, lifespace has typically been evaluated through observation or self-report measures such as questionnaires and diaries. However, these methods can be intrusive, inaccurate and time-consuming (Wan et al., 2013). The use of global positioning system (GPS) sensors to monitor and measure lifespace has recently emerged as an objective way of countering these limitations (Liddle et al., 2014; Schenk et al., 2011; Wan et al., 2013). Liddle et al. (2014) provided proof of principle of its relevance to this population using smartphone-based GPS data collection (Liddle et al., 2014).

This pilot study therefore aims to explore the feasibility of remotely collecting quantitative and qualitative information about the community lives including lifespace data of individuals with PD in their communities before and after DBS. It seeks to describe the broader impact of DBS on the community lives, quality of life, life satisfaction and lived experiences. Specifically, the research questions for this study are as follows: (1) What is the feasibility of using smartphone technology to measure the lifespace of people with PD before and after a clinical intervention (DBS)? and (2) What are their key lived experiences of DBS collected qualitatively and quantitatively in relation to lifespace, quality of life and life satisfaction outcomes?

Methods

Design

This study is a longitudinal mixed methods study with a convergent design, in which both quantitative and qualitative data were collected at up to three time-points, analysed simultaneously and then integrated (Guetterman, Fetters, & Creswell, 2015). A qualitative description design (Stanley, 2014) influenced by some underpinnings of descriptive phenomenology was applied within the qualitative aspects to richly and openly describe the experiences of participants around the time of undergoing DBS. The mixed methods research design was chosen to allow a detailed exploration of objective and subjective aspects of community lives of people in relation to DBS treatment. Value was placed on the ability to combine and explore the different aspects of the experience for individuals to gain a contextualised understanding of their

experiences and needs. Measures enabled comparison between timepoints, where open qualitative exploration enabled participants to indicate the key aspects of their experience, and their subjective view of it. Ethical approval was obtained from the relevant hospital (no. 1312) and university Human Research Ethics Committees (no. 2013000913) and all participants provided informed consent prior to participation.

Participants

Participants who were undergoing their first DBS surgery to treat PD at a private clinic were provided information about the study and invited to contact the research team if interested in participating (convenience sampling). Participants were eligible if they had a diagnosis of PD and were scheduled to undergo their first DBS surgery within the study period. Participants were excluded if they were unable to communicate in English sufficiently or did not anticipate being available for all data collections. All eligible, volunteer participants with surgeries scheduled between July 2015 and July 2016 were included.

Data collection and procedures

Data were collected from participants through self-report questionnaires, interviews and smartphone-based passive collection. Data collection occurred between July 2015 and January 2017, at up to three timepoints for each participant: pre (before DBS), post (3–6 months after DBS) and follow-up (9–12 months after DBS). Qualitative data about the lived experiences were gathered through semi-structured interviews. Depending on the location and preference of participants, interviews were conducted face to face or over the telephone, and were audiotaped. An interview guide was used to ensure consistency and was developed based on literature, earlier research by the group, with feedback incorporated from clinicians involved in DBS-related care. Participants were asked to reflect on their experiences with PD and DBS, their community lives, needs, and any anticipated and experienced changes. Participants also completed self-report questionnaires including disease-specific quality of life and life satisfaction.

Measures

Lifespace metrics. Lifespace metrics were obtained via geolocation data that were collected through an android smartphone, carried by participants for one week. Prior versions of these metrics have been generated and published in another study exploring if GPS data could indicate the lifespace of individuals with PD (Liddle et al., 2014). A custom application, Lifespace Tracker, present on the smartphone provided to participants (posted to regional participants), received a GPS signal and logged the longitude and latitude, speed, accuracy and time of day every 5 seconds while the application was on (Chenery et al., 2014). Data were streamed to a secure portal in 1 hour intervals. When no data were received, due to no GPS signal being available or the device being switched off, estimated geolocation values were generated through linear interpolation between data points to achieve a 5 second resolution. Linear interpolation provided a conservative indication of lifespace by connecting verified data points by the shortest distance. Calculation of lifespace metrics then occurred. A measure of the completeness of data was also generated for each data collection timepoint.

Lifespace area calculated daily and weekly geographic area of community travel in square kilometres. Geolocation points were used to give the perimeter of the area recorded. The area was then calculated by applying an algorithm that computes the area of an arbitrary shaped polygon. ***Time at home*** indicated the time use of participants, calculating the percentage of time spent at home out of total recorded time. ***Community trips*** indicated the number of times participants left and returned to their homes over the timepoint. For the purposes of the metric, and considering the confidence in resolution of GPS data, a single trip was defined as participants travelling a minimum of 500 metres, and staying away from the home location for at least 5 minutes.

Disease-specific quality of life, PD Questionnaire-8 (PDQ-8). The PDQ-8 is a short-form of the PD-39 which is a disease-specific, quality of life questionnaire for individuals with PD (Peto, Jenkinson, & Fitzpatrick, 1998). It has been used to evaluate patient outcomes after surgical treatments such as DBS and its reliability and validity have been well-established (Oxford University Innovation, 2016; Peto et al., 1998). Scores from the PDQ-8 can range from 0 to 100, with lower scores indicating higher disease-specific quality of life.

Life satisfaction, Personal Wellbeing Index-A (PWI-A). The PWI-A is an overall measure of life satisfaction and was designed for use with the general adult population (International Wellbeing Group, 2013; Wills, 2009). It is a self-report questionnaire providing a score out of 100. It demonstrates good test–retest reliability and a correlation of 0.78 with the Satisfaction with Life scale (Diener, Emmons, Larsen, & Griffin, 1985). The PWI-A provides a score representing subjective well-being, with higher scores indicating higher life satisfaction. The Australian normative range for individuals is 50–100 (International Wellbeing Group, 2013).

Severity of PD, Hoehn and Yahr (H&Y) Staging Scale. The H&Y is the most commonly and frequently used scale to describe the staging of PD. Studies have described a moderate to significant degree of inter-rater reliability and significant correlations with other measures of PD symptom severity (Goetz et al., 2004). There are five stages within the scale ranging from stage 1, where the symptoms are unilateral, with limited changes to functional abilities to 2, where bilateral symptoms are experienced, 3, where disability and postural changes occur, 4, where severe disability is experienced, but the person is able to walk unaided and stage 5 where the person is unable to move unaided.

Data analysis

Quantitative analysis

Quantitative data from all three timepoints were entered into an Excel database. Scores for each participant were tabulated together and graphed. The missing data were documented and descriptive statistics were generated for the data present. Lifespace metrics were generated for each participant based on custom algorithms written in C++ language and compiled to machine code.

Qualitative analysis

Interviews were transcribed verbatim and reviewed by the researchers for familiarity. An inductive content analysis was undertaken, which resulted in the emergence of main content areas, grounded in the data (Teddlie & Tashakkori, 2009). Key aspects of participants' experiences were described for each individual. Key content areas for each participant were developed by two researchers (TS, AS). Core shared aspects across all participants were generated through discussion between researchers (AS and JL) indicating five aspects of the DBS experience highlighted by all participants, and two larger content areas: *occupational participation* and *travel and home* indicating key features of community lives affected by DBS. Experiences for each participant and timepoint were summarised under key content areas and explored in relation to the self-report and lifespace measures.

Integration of data sets

The quantitative and qualitative data sets were first analysed separately, then compared and reviewed for similarities and differences. The integration enabled triangulation of different aspects of the experiences and outcomes over time for participants (Bryman, 2017). Integration and merging of the data sets was facilitated by a joint display of quantitative and qualitative findings. Pseudonyms have been used to maintain participant anonymity and direct quotations have been used for illustrative purposes. The separate aspects of the data types were explored and then drawn together according to individual participants in tabulation. In addition, individuals' maps and trajectories were separately explored and then drawn together data according to qualitative inductively derived core aspects. This study applied a number of core approaches recommended in mixed methods research including visual displays, triangulation of different data types and following threads that emerged from one data type into the others (Bryman, 2017; Dickinson, 2010; O'Cathain, Murphy, & Nicholl, 2010),

Results

Participants

Of the 13 potential participants who volunteered for the study, three participants were excluded as they were unable to provide any data prior to surgery. One participant was excluded after initial data collection as he did not undergo the surgery within the study period. Another had their data excluded from analysis as data were provided for only one timepoint. The final analysis included eight participants ranging from 35 to 73 years of age with mild to moderate PD. See Table 1 for baseline characteristics.

Lifespace data collection

There were a variety of reasons for patterns of participation in data collection. Of the eight participants, complete lifespace data were collected from two participants at all three timepoints. Two participants had missing lifespace data prior to the surgery (one declined to participate in any phone-based data collection, one had technical problems with this data collection) while four participants had missing lifespace data at the follow-up timepoint (three were unavailable to be contacted during the data collection period, one declined phone-based data collection).

Most participants described challenges in finding time for the additional data collection among many medical tests and appointments that are part of the DBS process. In addition, participants were often busy after DBS with medical and non-medical events including work and travel. Missing lifespace data due to technical problems or inaccessibility of non-acceptability of the data collection approach were of particular interest in this study. The participant who declined to participate in any phone-based data collection reported that he worried it would be too difficult to manage. Technical problems related to battery life

Table 1. Participant characteristics.

Characteristics	Descriptive statistics (n = 8)
Age	Median 68.0 years; IQR 7.5 years
Gender	
Male	6 (75.0%)
Female	2 (25.0%)
Geographic location	
Regional	5 (62.5%)
Metropolitan	3 (37.5%)
Living situation	
Live alone	1 (12.5%)
Do not live alone	7 (87.5%)
Employment	
In paid work	2 (25.0%)
Not in paid work	6 (75.0%)
Other medical conditions	
Other medical conditions	4 (50.0%)
No other medical conditions	4 (50.0%)
Hoehn and Yahr stage (baseline)	
Stage 1	2 (25.0%)
Stage 2	3 (37.5%)
Stage 3	3 (37.5%)
PDQ-8 scores (baseline)	Median 31.3; IQR 34.4
PWI-A scores (baseline)	Median 63.2; IQR 8.3

IQR: interquartile range.

or data not being collected despite attempts occurred on two occasions.

During data collection periods, participants were asked to collect lifespace data for one week, equating to approximately 168 hours of geolocation data. The median number of equivalent hours collected from participants was 147 hours (IQR = 138–170 hours), 139 hours (IQR = 119–167 hours) and 131 hours (IQR = 109–154 hours), at the pre, post and follow-up timepoints, respectively.

Quantitative results

Overall, there was a range of different change trajectories for lifespace, disease-specific quality of life and life satisfaction among the eight participants from pre to post timepoints (summarised in Table 2). Findings from qualitative interviews are also summarised with scores in the table, including insights into occupations, medication, symptoms, community movement and overall statements. Different change trajectories were also identified between the two participants who provided lifespace data over three timepoints, although both participants had an overall increase in total lifespace area and a decrease in time at home (Figures 1 and 2). A large difference in magnitude of lifespace scores was also observed between both participants,

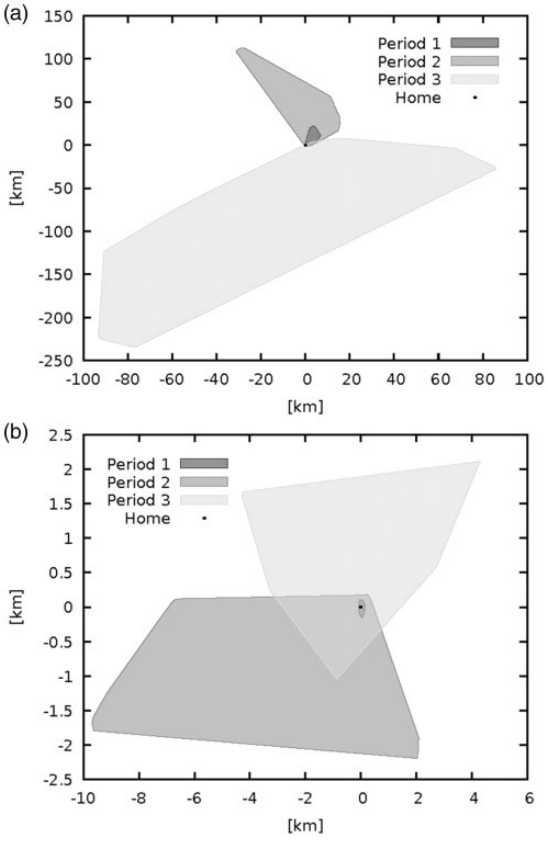

Figure 1. Individuals' lifespace area over time before and after DBS. (a) Lifespace area: Carl and (b) lifespace area: Kevin.

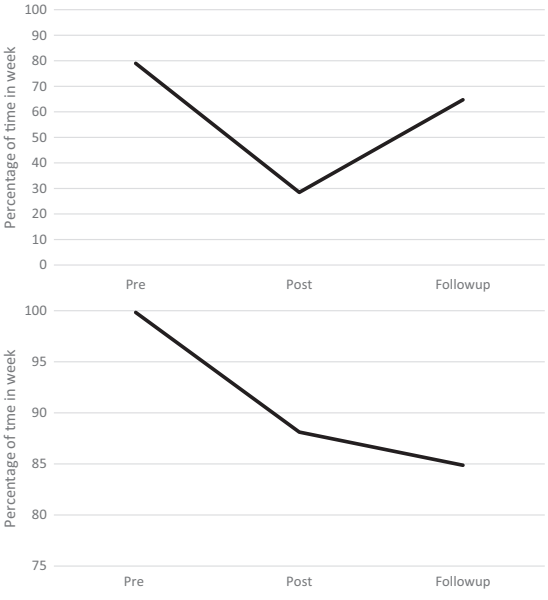

Figure 2. Individuals' percentage of time spent at home over time before and after DBS. (a) Percentage of time at home: Carl and (b) percentage of time at home: Kevin.

and it should be noted that the scales on the graphs are different in reflecting this.

Qualitative results

Participants were asked broad questions regarding their lived experiences with PD and DBS to capture their perspectives. Key content areas that emerged from the data reflected the key issues and experiences that were important to all participants. These were participation in occupations and travel and home. Each content area will be described using relevant verbatim quotations from participants. Participants also spoke about changes to medication (generally reduction or cessation) and symptoms (improvements and fluctuations) and these are summarised in Table 2.

Participation in occupations. Although participants were not directly questioned about their occupational experiences, all eight participants described the impact of PD on their occupations prior to DBS, and changes to their occupational engagement after the surgery. At the post timepoint, DBS was seen as providing most participants with renewed opportunities for participation in meaningful occupations. For example, Kevin described re-engaging in leisure occupations that he had discontinued prior to undergoing DBS including regaining his full driver's license, facilitating participation in valued occupations. He reported that it was 'more of the quality' rather than the quantity of his occupations that had improved. Similarly, Carl described being able to re-engage in self-care occupations independently, such as doing up buttons and tying shoelaces, due to improvements in hand and finger movement. He reported 'everything is easier and more pleasant than before'.

In contrast, at the post timepoint, Andrew described the cessation of his valued leisure occupations of walking and football, stating 'I was doing a few walks, but after a while it got too much, too strenuous. I've more or less given it up.' He attributed this to his experience of increased difficulty with lower limb movement.

At the follow-up timepoint, most participants continued to describe their enhanced engagement in various leisure and productive occupations. For example, Pam reported 'I have probably started doing more things by myself for example, going off to the shops and been out with friends a few times. Probably a bit more active.' Andrew reported continued difficulties with lower limb movement, however expressed that the surgery was a 'positive experience' overall. However, two participants expressed some disappointment at not being able to re-engage in particular occupations that had personal meaning. At the post timepoint, Kevin reported that he was considering re-engaging in tennis; however, at the follow-up timepoint, he described difficulties in doing so, reporting 'I can't play sport, that's one thing I can't do.' Despite this, he appeared pleased with his progress stating, 'Otherwise it's good.'

Travel and home. Participants described what a typical day was like for them, including occupations engaged in at home and in the community, and their usual travels. This content area helped to frame our understanding of changes to participants' routines and lives at a broader community level. Qualitative findings from this content area have been considered in conjunction with quantitative lifespace findings.

At the post timepoint, participants generally described feeling able to engage in the occupations of their choice, in their chosen locations. This included home-based occupations and travel into the community to engage in leisure or productive occupations. For example, Pam described her day as 'pretty relaxed because we're retired anyway' and 'might do some housework or go shopping or whatever I want to do really'. Both Keith and Eleanor also reported making more attempts to travel out of the house to engage in occupations such as community-based exercise. This was reflected in Keith's lifespace scores, which showed a large increase in total lifespace area of more than twice his baseline score, and a decrease in time at home. Eleanor's lifespace scores indicated a slight decrease in both total lifespace area and time at home.

In contrast, at the post timepoint, Kevin reported not travelling out of his home much after the surgery, stating '. . .I'm still spending a lot of time at home. I'm still not 100 per cent. I feel weak at times.' Despite this subjective feeling of spending more time at home, his lifespace scores indicated increased total lifespace area and decreased time at home. At the follow-up timepoint, Kevin did not specifically address his home-based or community-based mobility. His lifespace scores indicated a decrease in both total lifespace area and time at home from the post timepoint, although still representing increased total lifespace area and decreased time at home from the pre timepoint. Overall, he expressed feeling positive, stating 'Twelve months on, as I said the other day that, I said to the specialist, if you told me that I felt this good now I . . . would have called you a liar.'

At the follow-up timepoint, participants did not focus as strongly on describing usual travels or community mobility, however reported continued engagement in usual occupations. Carl summed this up, reporting 'It's just been really routine. Nothing startling, nothing drastic has happened at all.' Dan described engaging in fewer occupations at this

Table 2. Change in participant experiences and outcome measures from pre to post timepoints.

Participants (pseudonym)	Change in PDQ-8[†]	Change in PWI-A[‡]	Change in total lifespace area (km^2)[§]	Change in time at home (%)[¶]	Change in number of trips[#]	Participant experiences and perspectives (from semi-structured interviews
Kevin	−18.75	16.67	20.73	−11.71	2	a. ↑Quality of occupations and re-engagement in meaningful leisure activities, regained full driver's license b. No longer requires medication c. Improvements in general movements and strength d. Still feels weak and therefore spends time at home e. Surgery has had a large positive impact on his life
Brad	–	47.22	30.75	−10.94	1	a. Continued engagement in work b. ↓ medication c. Elimination of prior symptoms of shakes and involuntary movements d. Still spends most of his day at work e. Life has improved since surgery and is satisfied with experience
Eleanor	−18.75	16.67	−3.25	−2.01	0	a. Continued engagement in home-based occupations and community-based exercise b. Not described c. Still experiences symptoms on one side of her body, challenges with lower limb movement and speech d. Travels interstate for medical appointments and also attempting to be more mobile outside of home e. Pleased with outcomes of surgery and hopeful for the future
Pam	−12.5	37	−0.78	−1.06	−2	a. Continued engagement in productive and leisure occupations b. ↓ medication c. Improvements in walking and function, although still unsteady on her feet, able to adjust the stimulus as required d. Relaxed lifestyle with engagement in productive and leisure occupations e. Pleased with outcomes of surgery
Carl	−15.63	−15.27	2066.79	−50.49	−8	a. Able to engage in occupations more easily and pleasantly b. ↓ medication c. ↑ range of motion in hands and fingers d. Not described e. Some ↓ in functioning, but overall positive outcome
Keith	−43.75	0	69.69	−6.57	5	a. Gradually re-engaging in community-based exercise and other activities b. ↓ medication c. Fluctuating symptoms due to difficulties with fine tuning, but ↑ energy and ↓ tremors d. Travels interstate for medical appointments e. Overall ↑ quality of life
Andrew	21.88	−4.17	–	–	–	a. Discontinuation of some leisure activities due to difficulties with lower limb movement b. ↓ medication c. Fluctuating tremors, but still being fine-tuned, d. ↓neck pain Continued engagement in home-based occupations and travel into the community for leisure activities e. Regards self as hopeful for future

(continued)

Table 2. Continued

Participants (pseudonym)	Change in PDQ-8†	Change in PWI-A‡	Change in total lifespace area (km^2)§	Change in time at home (%)¶	Change in number of trips#	Participant experiences and perspectives (from semi-structured interviews
Dan	28.13	−45.83	–	–	–	a. Still engaging in home-based and work-based occupations as per usual b. Noted that he is still on medication c. Symptoms such as tremors and lower limb movement are fluctuating d. Frequent travel to city for medical appointments e. Unsure if outcomes of surgery have met expectations

Note: Participant experiences content areas.
a: Participation in occupations; b: Medication; c: Symptoms; d: Travel and home; e: Overall statement.
†PDQ-8 (Parkinson's Disease Questionnaire-8): Positive values indicate decrease in disease-specific quality of life.
‡PWI-A (Personal wellbeing index-A): Positive values indicate increase in life satisfaction.
§Total lifespace area: Positive values indicate increase in total lifespace area.
¶Time at home: Positive values indicate increase in time spent at home.
#Trips: Positive values indicate increase in number of trips.

timepoint due to increased symptoms, reporting '. . .normal days would be I'm not doing as much as I used to be doing. I'm sort of pretty slow at moving about the place at the moment. . . .' This was also reflected in his lifespace scores which showed a decreased total lifespace area and increased time at home from the post to follow-up timepoints.

Three participants spoke about the impact of having to travel to a metropolitan centre for medical appointments at the post timepoint. Keith reported 'It's a bit hard to do things. If I was in [city] metropolitan area, I could just pop in and see them.' At the follow-up timepoint, participants focused more on other aspects of their recovery and this issue was generally not raised. However when asked about anything that could help in this journey, Dan reflected that distance had been a challenge and it would have been advantageous being closer to the medical team. He explained '. . . it's a drive to get down there, so if they want to see you one day and they want to do some stuff on the machines, they haven't got really the next day to sort me out'.

Discussion

The findings of this study indicate that remotely measuring outcomes related to DBS including the lifespace of people with PD adds a more contextualised understanding to the typically measured clinical symptoms. The combination of qualitative and quantitative data gave scope to indicate the areas of concern for patient, beyond those typical, clinical outcome measures. Smartphone-based lifespace monitoring provided a non-invasive approach to understanding the impact of a treatment on community lives and outcomes over a 12-month period. In our sample, technical issues were raised at only two instances across all timepoints, with most missing data across all modes of data collection resulting from participants being unavailable during data collection periods due to being busy or travelling. As phones were posted to participants in regional areas and interviews conducted via phone, this was a relatively economical way of remotely monitoring participants' situations that did not require them to travel.

Collecting lifespace data in real time, rather than relying on recall may be particularly beneficial for people with PD who may have fluctuating and complex presentations of symptoms (Deuschl et al., 2006). Measuring lifespace through geolocation data provided insights into their lives at home and in the community, and can allow the more accurate measurement of lived community access and engagement (Liddle et al., 2014). Furthermore, the use of passively collected geolocation data allows for inclusion of participants living in different geographical locations who may not typically be able to participate in clinical trials or community monitoring (Collins, Al-Nakeeb, Nevill, & Lyons, 2012).

Participants demonstrated inconsistencies between the subjective and objective indicators of lifespace. For example, Kevin reported not travelling after the surgery, though his lifespace scores indicated increased lifespace area and decreased time at home. This provides insights into the impact of expectations and the difficulties in comparing current situations with remembered past ones. This has been previously reported for people living with PD experiencing DBS. Haahr et al. (2010) described participants developing a 'taken for granted body' view (p. 1234) where they

experienced improvements and forgot prior difficulties with function. This suggests a need for both objective and subjective input into lifespace to gain a meaningful understanding of participants' experiences in the context of community participation.

Despite the fact that the majority of participants reported improvement to symptoms and reduction in medication, the findings of this study describe the varied impacts of DBS on the community participation, life satisfaction and quality of life of people with PD. The range of change trajectories experienced by participants indicate the potential clinical complexity in supporting people experiencing DBS, along with the differing patterns of outcome measures combined with subjective perceptions of community life outcomes. Improvement in symptoms was not always experienced with improvement in wellbeing and participation. Studies of DBS outcomes have reported that this transition can be hard to manage, even when symptom changes are positive (Agid et al., 2006; Haahr et al., 2010; Mathers et al., 2016). In interviews conducted with participants with PD before and up to 24 months after DBS, participants reported dissatisfaction despite objective improvements in symptoms (Agid et al., 2006; Schupbach et al., 2006). This apparent contradiction has been attributed to the impact of unrealistic expectations, where the hopes of a cure or improvements beyond those anticipated by the clinical team affect satisfaction with the outcome (Clausen, 2010; Montel & Bungener, 2009). Difficulties adjusting and re-integrating into daily life could also impact on level of satisfaction with the treatment (Agid et al., 2006; Schupbach et al., 2006), demonstrating the individualised nature of PD and DBS experiences. Monitoring lifespace and lived experience over time helped to indicate the complexity of these experiences and to contextualise and deepen understanding of outcomes. As lifespace data can be visualised over maps of a person's local area, it may be possible to also use these created maps to help reflect on the client's recent community life experiences. Using maps to discuss community mobility can be a powerful and effective way to elicit needs and therapeutic goals (Liang, Liddle, Fleming, & Gustafsson, 2016) and using the client's own passively collected data, rather than interview-elicited data may enhance a grounded discussion, goal setting and problem solving process.

In descriptions of DBS experiences, all eight participants focused on occupations, describing the impact of PD and renewed opportunities for participation after DBS. Clinical trials have primarily used outcome measures assessing quality of life, motor function and severity of symptoms (Deuschl et al., 2006; Schupbach et al., 2013; Williams et al., 2010). The findings of this study add support for a more comprehensive approach that considers the importance of occupations, as recommended by Liddle et al. (2018) whose research indicated the need to include occupational evaluation and goal setting to support people experiencing DBS. This also potentially supports the relevance of occupational therapy involvement within the transitions related to DBS, to help in monitoring and optimising the community participation that participants indicated were of importance to their wellbeing.

The DBS experience for people living regionally was also described within this study. Some participants noted challenges with the need to travel for follow-up care and to adjust settings. Studies and clinical experience have indicated that individuals undergoing DBS have to commit time, energy and travel for both pre- and post-operative appointments, which is more difficult for individuals living in regional areas (Bell, Maxwell, McAndrews, Sadikot, & Racine, 2011). The use of remote monitoring technologies may support community-based monitoring of the daily lives of these individuals and can be used to facilitate timely and appropriate clinical follow-up.

The limitations of the current study should be acknowledged. This study was undertaken with a small sample of participants from one clinic. There were also missing data and only a limited number of participants provided complete data across the three timepoints. As such, caution is needed when generalising the results of this study to a broader population and context. Further research should involve a larger, more representative sample to investigate the emerging trends shown in this study.

Further research into lifespace as a measure of community participation has the potential to provide insights into the community lives of other groups.

Conclusion

The study was a pilot study exploring the potential role of collecting a range of community-based data as part of monitoring outcomes of DBS. Remotely monitoring lifespace in conjunction with subjective measures of quality of life and life satisfaction, and lived experience interviews provided a way of exploring the community lives and experiences related to DBS over time. The findings show that the experiences of individuals with PD undergoing DBS are complex and varied, and occupations and community participation form key aspects of these experiences. Further research could explore the impacts of DBS on occupations and community participation to gain a deeper understanding of the needs of people with PD and inform related clinical practice.

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