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How the ketogenic diet affects patients with Parkinson's disease: A descriptive phenomenological study

Authors:
Dawn R. White[1,2]
Tim A. White[3,4]
Melanie M. Tidman[5,6,7]

Affiliations:
[1]School of Health Professions, National University, San Diego, United States of America

[2]Glaser Center for Grounded Theory, Institute for Research and Theory Methodologies, Poway, United States of America

[3]School of Health Sciences, American Public University Systems, Charles Town, United States of America

[4]Department of Global Health Services and Administration, University of Maryland Global Campus, Adelphi, United States of America

[5]Department of Health Sciences, Liberty University, Virginia, United States of America

[6]Department of Health Sciences, A.T. Still University, Arizona, United States of America

[7]Department of Occupational Therapy, Nova Southeastern University, Florida, United States of America

Corresponding author:
Dawn White,
dwhite3@nu.edu

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Background: For individuals living with Parkinson's disease (PD), the earliest and most disruptive changes are often not tremor or rigidity, but a gradual loss of mental clarity, physical confidence and social ease that reshapes everyday life.

Aim: To explore how individuals with PD described changes in mental, physical and social quality of life (QoL) before and after participating in a 12-week low-carbohydrate, healthy-fat ketogenic dietary intervention.

Setting: The study setting consisted of participants recruited through the Colorado Parkinson Foundation, a community-based organisation supporting individuals living with Parkinson's disease and their caregivers. All participants resided in the United States during the study period.

Methods: Sixteen adults diagnosed with PD, aged 36–81 years, participated in this descriptive phenomenological study. Participants were recruited with assistance from the Colorado Parkinson Foundation and resided in the United States. Semi-structured interviews were conducted via Zoom before and after the dietary intervention to capture participants' lived experiences across time.

Results: Pre-study interviews yielded three major themes describing participants' experiences prior to dietary change, while post-study interviews yielded four major themes reflecting experiences following completion of the intervention. Participants described changes related to mental clarity, physical function, social engagement, metabolic health and relational support.

Conclusion: Findings highlight how metabolic-based dietary intervention was experienced in everyday life by individuals living with PD. Participants described improvements in mental clarity, physical function and social engagement that corresponded to observed changes in metabolic health, suggesting a meaningful connection between metabolic adaptation and QoL.

Contribution: Centring participant perspectives provides important patient-centred insight into how metabolic changes associated with a ketogenic diet (KD) intervention are experienced and integrated into QoL beyond clinical or biomarker outcomes.

Keywords: Parkinson's disease; nutrition; ketogenic diet; symptoms of Parkinson's disease; quality of life; Colaizzi; metabolism.

Introduction

For individuals living with Parkinson's disease (PD), the earliest and most disruptive changes are often not tremor or rigidity, but a gradual loss of mental clarity, physical confidence and social ease that reshapes everyday life.[1] These changes influence how individuals think, move, communicate and participate in daily routines, often long before the disease is fully understood or clinically stabilised.[2] As symptoms evolve, quality of life (QoL) becomes increasingly defined by the ability to adapt to cognitive, emotional and physical disruption rather than by motor impairment alone.[3]

Clinical management of PD remains largely symptom focused, relying on dopaminergic medications and device-based therapies to manage the motor functions of the disease.[4]

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Note: Additional supporting information may be found in the online version of this article as Online Appendix 1.

While these approaches may offer temporary relief, many individuals continue to experience cognitive fog, fatigue, mood disturbance and declining functional independence.[5] Over time, diminishing medication efficacy and cumulative treatment-related side effects further complicate symptom management and increase the overall burden of conventional PD treatment.[4]

Growing evidence suggests that PD involves systemic metabolic dysfunction, including impaired mitochondrial activity, altered cerebral energy utilisation, chronic inflammation and oxidative stress.[6] These metabolic abnormalities provide a biological rationale for interventions that target energy metabolism rather than neurotransmitter replacement alone. Dietary approaches that improve metabolic function and energy metabolism, such as low-carbohydrate and ketogenic (LCK) patterns, have therefore gained attention as potential adjunctive strategies that can influence both motor and non-motor experiences.

The present qualitative descriptive phenomenological study was designed to address this gap by exploring participants' described changes in mental, physical and social QoL following completion of the ketogenic intervention. Phenomenological inquiry allows individuals to describe their experiences in their own words, as they are lived. This approach makes it possible to understand how changes in energy, clarity, movement and social engagement are felt and interpreted.[7] Listening to these descriptions helps reveal how metabolic change becomes meaningful in everyday life for people living with PD.[7]

A 12-week LCK dietary intervention in adults with PD previously demonstrated significant improvements in select metabolic biomarkers and anxiety symptoms, with positive trends observed across both motor and non-motor outcomes.[8] While these quantitative findings support the metabolic relevance of dietary intervention in PD, they do not capture how individuals interpreted or integrated these changes into their daily lives. The present qualitative descriptive phenomenological study was designed to address this gap by exploring participants' personalised descriptions of their changes in mental, physical and social QoL following completion of the ketogenic intervention.

Background

The background section situates the study within the everyday experiences of metabolic change in PD. Rather than reviewing mechanisms or constructing conceptual models, the focus remains on how metabolic health is lived within daily life. This methodology provides a foundation for understanding participant accounts presented in the results.

Metabolic changes and everyday quality of life

For individuals living with PD, metabolic change is often experienced as having more or less energy from one day to the next, thinking more clearly at some times and struggling at others.[8,9] These day-to-day shifts affect how much people feel able to do, how often they need to rest and how they move through both physical and mental tasks.[10] Over time, these experiences become part of daily life and influence how easily individuals engage in activities of daily living, ultimately affecting overall QoL. In this context, QoL reflects the individual's ability to function physically, cognitively and socially within the constraints of PD.

Quality of life is experienced in ordinary moments, such as being able to focus during a conversation, move without fear of falling or complete familiar routines.[11] When the body feels unstable or depleted, people may feel less independent and less willing to engage with others or with activities they once enjoyed.[9] When the body feels steadier, those changes are often experienced as greater capability rather than simply fewer symptoms.

Ketogenic diet and metabolic adaptation

The ketogenic diet is experienced not as numbers or macronutrient targets but through how the body feels over time. Individuals may notice feeling fuller longer, having steadier energy, thinking more clearly or responding differently to familiar foods as the metabolic shifts take effect.[8,9] These changes are often recognised gradually as individuals pay attention to how the ketogenic diet shapes their bodily responses, daily routines and overall functioning.

Adapting to dietary change is rarely immediate or uniform. People often describe experimenting with foods, adjusting fat intake or finding personal patterns that help them feel better and stay consistent.[9] As motor and non-motor symptoms progress, these adjustments frequently occur within the context of family life, where caregiving responsibilities increase, and daily disruptions can weigh heavily on spouses and other caregivers.[12]

Ketogenic diet in Parkinson's disease

Previous ketogenic dietary intervention studies in PD have reported changes in weight, metabolic biomarkers, anxiety and symptom experiences.[13] Longer-term investigations have shown that some individuals continue to experience benefits as they learn to sustain dietary changes over time.[9] Together, these studies provide context for understanding how metabolic interventions, like the ketogenic diet, may influence daily life in different ways.

At the same time, much of this research focuses on measurable outcomes rather than personal meaning.[14] Laboratory values and symptom scores can show change without revealing what those changes actually feel like.[14] As a result, important aspects of lived experience often remain unexplored.[15]

Purpose of the study

The purpose of this descriptive phenomenological study was to explore how a ketogenic diet affects the experiences of individuals living with PD by examining changes in metabolic health and QoL. Qualitative exploration was conducted before and after participation in a 12-week LCK intervention. The study focused on participants' experiences of changes in mental clarity, physical function and social engagement before and after the intervention. This study sought to capture how metabolic changes were experienced and how this impacted everyday life.

Research methods and design

A descriptive phenomenological approach guided the qualitative exploration of lived experiences among individuals with PD who participated in a 12-week LCK dietary intervention. Semi-structured interviews were conducted before and after the intervention, allowing participants to describe changes over time as they were experienced in everyday life. The qualitative component was embedded within a broader metabolic intervention framework while maintaining analytical independence appropriate to phenomenological inquiry.[16]

Participants followed a whole-food, low-carbohydrate, healthy-fat ketogenic diet designed to induce nutritional ketosis. Carbohydrate intake was limited to approximately 16 g/day (3% – 4% of total calories), with macronutrient targets of roughly 78% fat and 17% protein. Participants received education, meal plans and ongoing weekly support, and adherence was monitored through food logs and weekly blood glucose and ketone measurements, with ketosis defined as blood ketones >0.5 mmol.[8]

Participants and setting

Each participant (n = 16) was an adult diagnosed with PD who had enrolled in a 12-week LCK dietary intervention. Individuals ranged in age from 36 years to 81 years and represented Hoehn and Yahr stages 1 to 4 (Table 1). Participants resided in the United States and were recruited with assistance from the Colorado Parkinson Foundation. Participants in this qualitative study are a continuation of that cohort and were purposively selected based on having completed the intervention and willingness to describe their experiences.

Given that the sample was selected through participation in the parent study, no additional recruitment occurred. Rather than recruitment to saturation, thematic sufficiency was assessed through ongoing analysis, with consistent patterns observed across participants and no substantially new experiential insights emerging after approximately the twelfth interview. Subsequent interviews reinforced existing themes without contributing novel thematic content.

TABLE 1: Participant demographic information.

Participant ID	Age (years)	Sex	State	Hoehn and Yahr stage
002	66	Male	Colorado	I
004	72	Female	Colorado	I a
007	78	Male	Colorado	II a
008	57	Male	Colorado	II
010	74	Male	Colorado	II
012	67	Male	Colorado	I a
013	81	Male	Colorado	II a
014	54	Female	Arizona	II
015	67	Female	Colorado	I
016	63	Male	Colorado	I a
018	72	Male	Colorado	II
019	54	Male	Colorado	III
020	57	Male	Colorado	I a
021	36	Female	Idaho	II
022	79	Female	Tennessee	III a
023	54	Male	Colorado	II a

ID, identification.

Eligibility criteria included a confirmed diagnosis of PD, the ability to speak and understand English, and a body mass index above the clinical cutoff of 18.5 for underweight classification. Participants were required to complete the 12-week intervention and to obtain permission from their primary care provider and neurologist before enrolment. These criteria were consistent with those used in the parent intervention study, with no additional exclusion criteria applied for the qualitative component. All participants provided informed consent before participating in interviews.

Interviews were conducted remotely via a secure Zoom platform, allowing participants to engage from their homes. This setting supported accessibility and continuity across pre- and post-intervention interviews. Conducting interviews in familiar surroundings facilitated participant comfort.

Data collection

Data collection consisted of 16 semi-structured interviews lasting approximately 30 min. A single researcher conducted all interviews to maintain continuity. Interviews were prescheduled, conducted and audio-recorded via Zoom and then transcribed by Rev.com under a signed confidentiality agreement. Participants who were unable to communicate verbally completed a qualitative questionnaire and returned it to the researcher.

The interviewer has a background in health science and prior experience in metabolic and KD research. During the interview, field notes were taken to capture keywords, contextual observations and impressions deemed necessary by the interviewer. Field notes are the 'researcher's private, personal thoughts, ideas, and queries regarding their research observations and interviews'.[17] The interviewer entered the study with an awareness of reported metabolic and symptomatic benefits associated with ketogenic dietary interventions, including expectations of potential

improvements in energy, cognitive clarity and physical functioning. These notes were used reflexively to support bracketing by identifying and documenting preconceptions, allowing the researcher to remain attentive to participants' descriptions as they were expressed. Field notes were revisited during analysis to support coding decisions, help set aside prior assumptions and ensure that emerging interpretations remained grounded in the data. Interviews were conducted with all participants before and after completion of the nutritional intervention. Interviews were guided by a semi-structured interview approach designed to elicit participants' descriptions of their lived experiences before and after the dietary intervention. A consistent interview guide was used across pre- and post-intervention interviews, with questions adapted only to reflect timing (i.e. experiences before the diet and experiences following completion). Pre-intervention interviews focused on participants' mental, physical and social QoL, as well as expectations for the study. Post-intervention interviews explored changes in these domains as described by participants, as well as their lived experiences with the LCK, including benefits, challenges and overall impressions. Follow-up prompts were used as needed to clarify meaning and deepen descriptions.

Data analysis

Upon receipt of transcripts from Rev.com, recordings were reviewed alongside transcripts to ensure accuracy and to support immersion in the data. All 16 transcripts were uploaded into ATLAS.ti, a computerised data analysis software program used to facilitate organisation and coding.[18] Familiarisation with the data occurred through repeated reading prior to formal analysis.

Data were analysed using Colaizzi's (1978) seven-step method, which includes: '1. Familiarisation, 2. Identifying significant statements, 3. Formulating meanings, 4. Clustering themes, 5. Developing an exhaustive description, 6. Producing the fundamental structure, and 7. Seeking verification of the fundamental structure'.[19] This approach ensured that analysis remained grounded in participant descriptions while allowing patterns to emerge across accounts. In this process, meanings were derived directly from participants' statements, with care taken to remain close to the original language and not extend interpretation beyond what was expressed during the interviews. Following this method ensured no steps are missed during the analysis while properly exploring their experiences.[20]

Initial coding focused on identifying significant statements related to participants' experiences before and after the dietary intervention. Codes were compared across transcripts and refined as analysis progressed, allowing themes to develop through constant engagement with the data. Analytic decisions were discussed among the research team to support the credibility and coherence of the findings.

Trustworthiness and rigour

Trustworthiness was established by addressing credibility, dependability, transferability and confirmability throughout the study.[21] Two members of the research team independently reviewed transcripts and participated in the coding process, with codes revised as additional transcripts became available.[22] Credibility was supported through member checking, allowing participants to review transcripts and request corrections or clarifications,[23] as well as peer debriefing among research team members. An audit trail and systematic documentation of analytic decisions were maintained to support dependability and confirmability.[24] Reflexive journaling and bracketing were used throughout the study to identify and manage potential researcher bias. Together, these strategies ensured that findings remained grounded in participants' descriptions while supporting the rigour and transparency of the analytic process.

Ethical considerations

The study received ethical oversight approval from the Institutional Review Board at A.T. Still University (Protocol number: 2020-058) prior to data collection. Informed consent was obtained from all participants in accordance with the principles of the Declaration of Helsinki.[25] Before interviews began, each participant confirmed their willingness to participate and verified that they had signed the informed consent. Participant confidentiality and data security were maintained throughout the study. Audio recordings, transcripts and related documents were stored on password-protected devices accessible only to members of the research team. Identifying information was removed from transcripts, and participant data were coded to protect privacy. The study was registered with the International Standard Randomised Control Trial Number (ISRCTN) Registry through the BioMed Central (BMC) system under reference number: 38010. Registration supported transparency and public accountability of study procedures. All ethical requirements related to participant protection and data handling were observed throughout the study. A completed Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist is provided as supplementary material to support transparency and methodological rigour (Online Appendix 1).

Results

The results are presented in two sections corresponding to interviews conducted before and after the dietary intervention. Pre-study interviews reflect participants' expectations and lived experiences before the dietary change, while post-study interviews capture participants' experiences after completing the intervention. Themes are presented separately for each time point to allow participant perspectives to be heard within their original context.

Pre-study

At the onset of the interview process, participants were asked to describe their expectations for participating in the study. Expectations commonly included hopes for symptom reduction, medication adjustment and weight loss. These expectations reflected participants' understanding of their current challenges before the dietary change.

Reduction of symptoms

Participants frequently expressed a desire for improvements in their overall QoL and PD symptoms:

> 'I just want to see, well, if it improves my quality of life and improves my symptoms. I'm sure losing some weight will help me.' (Participant 014)

One participant described hoping for improvements in physical and psychological symptoms:

> 'I guess anxiety, then physical symptoms, tremor would be really great if it would improve that.' (Participant 021)

This was further reflected in the participant's description of the relationship between anxiety and tremor, noting:

> 'I think anxiety definitely makes my tremor worse'. (Participant 021)

Reduced medication

Several participants hoped that dietary changes might reduce medication burden or improve medication effectiveness. For some, participation in the study also represented an opportunity to explore emerging dietary approaches that might complement existing treatment strategies:

> 'Well, I'm hoping that we can adjust my medication to make it more effective, and find out more about Parkinson's, if there's things we can do. We've heard that there's a possible link between Parkinson's and this keto diet that may improve some things about Parkinson's. We hope it does.' (Participant 007)

Weight loss

Weight loss was another commonly cited expectation prior to beginning the intervention:

> 'Perhaps lose some weight, which I desperately need to do. I've gained a whole bunch in the last six to seven months, which is part of the physical problem, too. Physical discomfort. So, I would say interesting information in the sense that I spent my time well.' (Participant 015)

As the pre-study interviews progressed, they yielded three major themes, including: (1) something's not right; (2) standing on my own two feet; and (3) out of my control.

Theme 1: Something's not right

Before the dietary intervention, participants often described an early sense that something felt wrong, even before receiving a formal diagnosis or understanding what was happening. These experiences were commonly expressed as a lack of mental clarity, difficulty articulating thoughts and a vague awareness that daily functioning had changed. For many participants, these early changes marked the beginning of emotional uncertainty and frustration.

One participant reflected on the early period of uncertainty before diagnosis:

> 'I was diagnosed in the fall of 2016, but I had been complaining of vague things for about a year.' (Participant 004)

Brain fog

Participants frequently used the term 'brain fog' to describe difficulty thinking clearly or expressing themselves. Although not a clinical term, it helped participants communicate experiences that affected conversations, decision-making and confidence in social interactions. The following quotes reflect how participants described these cognitive challenges in their own words:

> 'I don't speak up much at all, because I don't feel like my mind is working good as far as forming sentences out of my mouth.' (Participant 010)

Other participants described becoming aware of these difficulties during everyday interactions:

> 'Sometimes when I am talking, I'll pause or stutter or say something that I don't mean. I think I say one thing, but everyone else was like, "No, that's not what you said." So, I know there is some kind of glitch.' (Participant 014)

Stress, anxiety, and depression

About 75% of the participants discussed episodes of stress, depression or anxiety, either as a historical problem or one that occurred just before or immediately following their Parkinson's diagnosis. These emotional experiences were often intertwined with physical symptoms, making it difficult for participants to separate psychological distress from motor changes. Participants also reflected on how these feelings influenced their outlook on the future:

> 'My tremors I always associated with anxiety. That's what I thought it was from. I tried to differentiate what was actually anxiety or tremors from Parkinson's disease. [*I found it was*] hard to disassociate those two; [*however,*] I think anxiety definitely makes my tremors worse.' (Participant 012)

Some participants realise they will have difficulty moving forward and wonder how their lives will change or how they will overcome obstacles:

> 'There are some days when there are higher levels of ... Well, I'm going to call it anxiety. And perhaps you kind of doubt what the future holds for you. You look into the way things used to be, meaning pre-Parkinson's, and you compare that to what the situation is now, and you certainly can see some deficiencies that you wish you could overcome.' (Participant 016)

Theme 2: Standing on my own two feet

This theme reflects the effort required to maintain independence amid balance challenges, movement instability and fear of falling. Before the dietary intervention, participants frequently described their physical experiences in terms of movement, balance and the ongoing demands of remaining independent. Concerns about falling, freezing and physical instability shaped their approach to daily activities, influencing decisions related to exercise, mobility and personal safety.

Balance

Balance difficulties were a common concern among participants. Many described episodes of freezing, unsteadiness and fear of falling despite strong efforts to stay active. The following quotes illustrate how balance challenges affected everyday movement:

> 'I didn't quite finish on the things that I don't do too well. My balance is very tied in with the freezing, and I've fallen a lot. Unfortunately, I know how to fall pretty good from sports and stuff, and I haven't gotten hurt anyhow. But I fell probably 80 to 100 times since I got diagnosed.' (Participant 007)

Participants also described recognising new physical limitations as their disease progressed:

> 'I do have limitations. I have some balance issues. I have had a couple of really bad falls. And I have a lot of pain and muscle cramping, muscle spasms.' (Participant 014)

Exercise routine

Many participants emphasised the importance of maintaining regular exercise to prevent physical decline. Exercise routines were described as intentional efforts to preserve strength, balance and mobility. For some, the fear of losing movement served as motivation to remain physically active:

> 'I punch the big bag and do Parkinson's exercises.' (Participant 010)

Listening to them describe their experiences, there was a sense of panic that if they stopped moving, their PD would take over:

> 'I try to stay in shape physically. I work out at the Y three times a week, and there I walk, run on a treadmill three miles, and lift weights.' (Participant 020)

Dystonia

Some participants described dystonia as a disruptive and unpredictable physical symptom. These involuntary muscle contractions affected daily functioning and, in some cases, interfered with vision and routine tasks. One participant described how dystonia affected his eyes:

> 'I blow my nose and close my eyes, and then I can't even get my eyes open. I have dystonia in my eyelids. Sometimes I have to physically open them up so I can see again.' (Participant 018)

Theme 3: Out of my control

This theme reflects the experience of reduced control over how one's body is experienced and responded to in social situations. Before the dietary intervention, participants often described social experiences as unpredictable and challenging to manage. Visible symptoms and concerns about safety shaped public settings, interactions with others and changes in social identity. These experiences contributed to feelings of limited control in everyday social life.

Introvert

Several participants described themselves as introverted, often linking this preference to physical symptoms or fear of falling. Limiting social interaction was sometimes experienced as protective rather than isolating. Participants described adjusting their social lives in ways that felt manageable:

> 'I am [*an*] introvert and probably an extreme introvert. I don't feel a great loss of company.' (Participant 015)

Some described how their bodies showed signs even when they wished to remain unnoticed:

> 'It's like I tell people: I'm not a very good poker player before Parkinson's. I'm a horrible poker player now. I can keep a straight face, but the rest of my body tells you what hand I'm holding.' (Participant 016)

When asked about the social life, one participant responded:

> 'I don't know. I don't like people. So, probably hang out together and have dogs.' (Participant 019)

Fine with close friends

Despite broader social limitations, participants often described feeling comfortable with close friends and family. Familiar relationships reduced the need to explain symptoms or manage public perceptions. These environments were experienced as safer and more accepting:

> 'I'm really comfortable in my current situation and the people that I'm around, I don't feel I have to explain myself to anybody.' (Participant 021)

This sense of comfort was echoed by others:

> 'As far as social interaction with friends that I've known for a long time, I feel fine getting together.' (Participant 020)

Post-study

Following completion of the 12-week LCK dietary intervention, participants were asked to reflect on how they felt and whether they noticed changes in their mental, physical or social QoL. Participants described both challenges and benefits associated with the intervention, including adjustments to daily routines and eating habits. From the post-study interviews, four major themes emerged.

Some participants described initial efforts to track food intake and adjust habits while also recognising the value of working towards improved health:

> '"We had to keep track of all the meals that we ate every day. That seemed to provide a little additional stress or anxiety, because it was one more thing that I had to keep track of throughout the day, every day. That was a little bit more stressful than not doing it." However, "I knew that I was working towards trying to work on a healthier lifestyle diet. So, from that standpoint, that was positive, and that was a benefit, and knowing that the foods I was eating could potentially have good effects and good impacts on my Parkinson's, that was positive also. They were the things that were positive in the overall diet as well."' (Participant 020)

Others described the dietary transition as easier than expected:

> 'It was easy, I thought I'd have trouble with bread and sugar, but I didn't.' (Participant 013)

They continued to say they had little difficulty buying or preparing foods associated with the ketogenic diet.

Theme 1: Less foggy, thinking more clearly

Participants described changes in mental clarity and emotional resilience following the dietary intervention. Many reported feeling less foggy, more focused and better able to manage daily demands. Participants described these improvements as a return to clearer thinking and greater emotional steadiness, changes that were also observed by family members:

> 'My mental quality of life has taken a bit of an improvement, a turn for the positive. Within a week or two, after the beginning of the ketogenic diet, there seemed to be a little higher level of clarity that was even mentioned or noted by my wife and my daughter. It seemed like there was a brain fog that I had there, and I don't know how better to describe it, but it just seemed to lift, and things were so much like they used to be.' (Participant 016)

Participants also described changes in their attitudes and outlooks on life:

> 'Better than before. It's less foggy, and I think that I've got a better attitude. I can think better, and I think that can make my thoughts come out of my mouth better.' (Participant 018)

Theme 2: Watch me move: Changes in movement and physical function

Participants described changes in physical movement, balance and overall ease of mobility following the dietary intervention. Many spoke about feeling more stable, experiencing less stiffness and having greater energy to engage in physical activities. These changes were experienced as increased confidence in movement and a renewed ability to participate in daily tasks:

> 'I lift weights, and I walk/jog combination. A fast walk or slow jog.' (Participant 007)

Balance

Participants described noticing changes in balance and stability after the intervention. For some, these changes occurred alongside other lifestyle efforts, such as physical therapy and weight loss, contributing to greater confidence during movement and daily activities:

> 'I went to an outdoor three-day concert with my family. It was just adults. There was a lot of walking involved … I was actually super proud of myself because [*I am*] typically very self-conscious. Often, I was walking up a hill with tonnes of people, eyes on me and I have this really gimpy walk. I just didn't really care. There was nothing I could do about it, so be it. That was a big thing for me to be able to just not worry about it.' (Participant 023)

Ease of movement

Participants described moving with greater ease and less physical discomfort than before. Increased energy and reduced stiffness allowed some to resume activities they had previously limited or avoided. These changes were experienced as meaningful improvements in everyday life:

> 'I am less achy. I'm less groggy. I have more energy, a lot, lot more energy, which has allowed me to start gardening again this year, which I wasn't sure I was going to be able to do.' (Participant 023)

Some participants reflected on how combined efforts, such as physical therapy and dietary change, contributed to feeling better physically:

> 'Stability is better. I was doing physical therapy when I started the diet and I finished that. I had quite a bit of improvement. As I started losing weight it seemed to really help a lot.' (Participant 014)

Theme 3: Feeling healthier through physical and metabolic changes

Participants described changes in their physical and metabolic health following the dietary intervention. These changes were often reflected in weight loss, improved laboratory values and medication adjustments. Participants spoke about these shifts in practical, everyday terms, often linking them to feeling healthier, lighter and more capable in daily life:

> 'I knew that I was working towards trying to work on a healthier lifestyle diet. So, from that standpoint, that was positive, and that was a benefit.' (Participant 020)

Weight loss

Weight loss was commonly described as noticeable and meaningful. Participants connected changes in body weight and clothing to increased physical comfort and mobility. These changes were often reinforced by feedback from others:

> 'Well, there's nothing like losing almost 50 pounds.' (Participant 023)

Participants also noticed changes reflected in the scale and waist measurements:

> 'Yes. I lost about 15 pounds, so I am at 170, probably an inch around my waist that I've lost as well.' (Participant 008)

Others described external recognition of their physical changes:

> 'I went from a 41 waist down to 35 and three-quarters. Everybody's noticed a difference.' (Participant 012)

Laboratory changes and medication adjustments

Some participants described satisfaction with improvements seen in laboratory values and medication management. These changes were experienced as reassurance that their efforts were producing tangible health benefits. Participants also described shared engagement with spouses during this process:

> 'I would say, as far as my labs go, it definitely exceeded my expectations. I was really surprised at how my numbers changed.' (Participant 021)

Spouses often participated in reviewing health information and supporting continued effort:

> 'When I see the medical report … with such good results, it's, I'm willing to work with him as long as he's willing to keep doing it.' (Participant 013)

Theme 4: I have such gratitude

Participants frequently expressed appreciation for the support they received throughout the dietary intervention. Gratitude was directed towards family members, particularly spouses, who assisted with meal preparation, offered encouragement and participated. These relationships were described as central to sustaining dietary change:

> 'I have a really good support system here, my wife and my daughter. My wife cooks some good ketogenic diet meals, which made a big difference.' (Participant 012)

Many participants describe their support group system as feeling like family involvement rather than individual effort:

> 'I'd say that it was like 80% family because [*my spouse*] did about 80% of the keto diet with me.' (Participant 004)

Discussion

This study aimed to explore how individuals with PD described their experiences before and after participation in a 12-week LCK intervention. Participants' accounts centred on changes in mental clarity, physical functioning and social engagement as they were experienced in everyday life. These descriptions highlighted the relevance of metabolic health from the perspective of those living with PD, rather than solely through clinical metrics.

Participants described increased energy, reduced cognitive fog and greater ease in daily activities, experiences that aligned with observed improvements in metabolic health markers. Existing research on ketogenic dietary interventions in PD has documented changes in metabolic markers and symptom measures.[9] Still, these findings are often presented without regard for how patients experience such changes. The present study extends this literature, showing that metabolic change was experienced as shifts in capacity, confidence and bodily reliability rather than as abstract physiological improvement.[8,9,26]

Experiences of clearer thinking and improved emotional outlook echoed what has been described in the literature as central to QoL in PD.[14] Cognitive symptoms such as fatigue, difficulty concentrating and brain fog are frequently discussed in relation to metabolic disruption,[27] yet these associations are often framed clinically rather than through everyday experience. The accounts in this study illustrate how changes in mental clarity were felt through ordinary moments of communication, confidence and emotional steadiness, shaping how individuals understood their ability to engage with daily life.

Experiences related to movement, balance and physical confidence were closely tied to how individuals understood their QoL[28] while living with PD. Physical ease was described not simply as improved mobility, but as feeling more capable of engaging in activities that mattered, such as exercise, hobbies and daily tasks, which aligns with prior work linking metabolic health to functional experience in PD.[8,9]

Attention to bodily signals, such as weight changes, clothing fit and laboratory results, appeared to shape how individuals made sense of their health over time.[29] Rather than being viewed solely as clinical outcomes, these indicators were often experienced as reassurance that efforts towards dietary change were meaningful, consistent with literature on metabolic self-management and feedback in chronic illness.[30] This embodied feedback seemed to support motivation and sustained engagement by helping individuals trust their body's responses.

Changes in social engagement reported by the participants point to a close connection among physical confidence, cognitive clarity and willingness to participate in social life. Prior research has shown that social withdrawal, stigma and reduced participation are common concerns for individuals with PD, particularly when symptoms feel visible or unpredictable.[31,32] The experiences described in this study suggest that feeling steadier in one's body and thinking more clearly may help individuals feel more comfortable re-entering social spaces and maintaining valued relationships.

Family involvement and caregiving support emerged as an essential context shaping how dietary change was experienced and sustained.[33] Participants' expressions of gratitude towards spouses and family members reflect prior research showing that, as motor and non-motor symptoms progress, caregiving demands increasingly affect daily routines and shared decision-making.[34] These accounts suggest that metabolic interventions are often lived not as individual efforts, but as relational processes embedded within family life.

Study limitations and future research

Several limitations should be considered when interpreting these findings. Participants were drawn from a previously

completed quantitative pilot study of an LCK intervention, yielding a small, self-selected sample of individuals motivated to engage in dietary change. As such, findings may not be transferable to all individuals living with PD, particularly those with different levels of interest or access to dietary interventions.

Experiences were captured through self-report and reflect participants' descriptions rather than objective measures of change. The qualitative design was not intended to evaluate efficacy or establish causal relationships but to describe lived experience before and after dietary intervention. This approach prioritises depth of understanding over generalisability.

Although many participants described positive changes associated with the intervention, not all experiences reflected benefits across all domains. Some participants described challenges with dietary adherence, increased effort related to tracking requirements or more limited symptom changes. These variations were incorporated into the analysis; however, given the self-selected nature of the sample and the structured dietary intervention, individuals who discontinued or experienced greater difficulty may be underrepresented. As such, the findings may reflect a more favourable range of experiences and should be interpreted within this context.

Future research should continue to examine metabolic interventions in PD using qualitative and mixed-methods designs with larger, more diverse samples. Longitudinal studies that follow participants across different stages of disease progression and caregiving contexts may further illuminate how metabolic change is experienced over time. Integrating lived experience with metabolic and clinical outcomes will remain essential for understanding how dietary interventions are meaningfully incorporated into everyday life.

Conclusion

This descriptive phenomenological study provides insight into how individuals with PD experienced metabolic and QoL changes before and after participation in a 12-week LCK intervention. By centring lived experience, the findings highlight how metabolic change was understood through everyday shifts in mental clarity, physical confidence, social engagement and relational support, rather than solely through clinical outcomes. These perspectives underscore the importance of incorporating patient experience into metabolic health research to better understand how dietary interventions are meaningfully lived and sustained in daily life.

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Competing interests

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CRediT authorship contribution

Dawn R. White: Conceptualisation, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision, Visualisation, Writing – original draft, Writing – review & editing. Tim A. White: Conceptualisation, Formal analysis, Project administration, Writing – original draft, Writing – review & editing. Melanie M. Tidman: Conceptualisation, Investigation, Project administration, Resources. All authors reviewed the article, contributed to the discussion of results, approved the final version for submission and publication and take responsibility for the integrity of its findings.

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Data availability

The data that support the findings of this study are not openly available and are available from the corresponding author, Dawn R. White, upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and are the product of professional research. They do not necessarily reflect the official policy or position of any affiliated institution, funder, agency, or that of the publisher. The authors are responsible for this article's results, findings, and content.

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