



Pacemaker Implants and Their Influence on the Daily Life of Patients with Dementia with Lewy Bodies: A Qualitative Case Study

Isak Heyman · Annika Brorsson · Torbjörn Persson ·
Elisabet Londos

Received: March 24, 2023 / Accepted: May 31, 2023 / Published online: June 16, 2023
© The Author(s) 2023

ABSTRACT

Introduction: Dementia with Lewy bodies (DLB) is an incurable form of dementia associated with detriments to the daily life of patients and carers from their family. Symptoms of orthostatic hypotension, syncope, and falls are supportive of DLB diagnosis. These symptoms may also be present among people with sick sinus syndrome (SSS), and subsequent pacemaker treatment to manage bradyarrhythmia is associated with improved cognitive function. The prevalence of SSS seems to be higher among

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s40120-023-00513-5>.

I. Heyman (✉) · A. Brorsson · E. Londos
Department of Clinical Sciences Malmö, Lund
University, Malmö, Sweden
e-mail: isak.heyman@med.lu.se

A. Brorsson
Family Medicine, Lund University, Malmö, Sweden

A. Brorsson
Centre for Primary Health Care Research, Skåne
Region, Malmö, Sweden

T. Persson
Department of Cardiology, Skåne University
Hospital, Malmö, Sweden

E. Londos
Division of Clinical Geriatrics, Department of
Neurobiology, Care Sciences and Society, Karolinska
Institute, Stockholm, Sweden

people with underlying Lewy body pathology compared to the general age-matched population (5.2% vs. 0.17%). To our knowledge, how people with DLB and their family carers may experience pacemaker treatment to manage bradyarrhythmia has not been previously reported. Therefore, the aim of this study was to explore how people with DLB experience daily life following a pacemaker implant to manage associated symptoms of bradyarrhythmia.

Methods: A qualitative case study design was used. Two men with DLB and their spouse carers were repeatedly interviewed as a dyad within 1 year following implant of a dual-chamber rate-adaptive (DDD-CLS) pacemaker to manage SSS in the men. Content analysis was used to assess the qualitative interview data collected.

Results: Three categories emerged: (1) *gaining control*, (2) *maintaining a social life*, and (3) *being influenced by concurrent diseases*. Less syncope/falls and remote pacemaker monitoring increased a sense of control in everyday life, while perceived physical and/or cognitive improvements influenced social participation. The men were still affected by concurrent diseases, which continuously influenced each couple's daily life.

Conclusion: Identifying and managing concurrent bradyarrhythmia through a pacemaker implant could improve well-being for people with DLB.

Keywords: Bradyarrhythmia; Dementia with Lewy bodies; Pacemaker; Patient perspective; Sick sinus syndrome; Qualitative research

Key Summary Points

Sick sinus syndrome seems to be more common among people with DLB compared to the general population and may mimic features of DLB, including syncope and falls.

Symptoms of DLB are associated with detriments to the daily life of affected people, and falls are the second most common cause of hospitalization.

Our aim was to explore how people with DLB experience daily life after a pacemaker has been implanted to manage associated symptoms of bradyarrhythmia.

Within the year after receiving a pacemaker implant the participants experienced a decrease in syncope/falls, improvements in physical and/or cognitive functioning and difficulties in living with various and sometimes interplaying diseases.

Identifying and managing concurrent bradyarrhythmia through a pacemaker implant could enhance functioning and health by relieving mimicking features of DLB.

INTRODUCTION

Key summary points

Dementia with Lewy bodies (DLB) is the second most common form of neurodegenerative dementia [1], caused by intracellular deposits of the misfolded protein alpha-synuclein. These misfolded proteins are found in both the central and peripheral nervous systems [2]. DLB shares similar neuropathological processes with

Parkinson's disease and these conditions are collectively known as Lewy body disease (LBD)[2]. Compared to people with Alzheimer's disease, people with DLB experience lower quality of life, worse functional abilities, higher caregiver distress, and increased risk of hospitalization [3–7].

Dementia is an essential feature for diagnosis of DLB, and is characterized by progressive attention–executive and visuospatial cognitive decline, with memory often being well preserved [8]. Diagnosis also relies on a tetrad of core clinical features: (1) fluctuations in cognition with alterations in attention and alertness; (2) spontaneous features of parkinsonism; (3) REM-sleep behavior disorder; and (4) visual hallucinations [8].

In clinical practice, diagnosis of DLB is supported by clinical features of orthostatic hypotension, syncope, and falls [8], with falls reported as the second most common cause of hospitalization [9].

Without an existing cure, current pharmacological and non-pharmacological management strategies are symptomatic and aim to improve quality of life [10]. In addition, it is important for clinicians to recognize other factors that could improve well-being of people with dementia.

Several case reports have described that bradyarrhythmia can mimic features of LBD [11–14]. Bradyarrhythmia due to sick sinus syndrome (SSS) may clinically manifest with light-headedness, fatigue, syncope, and falls, and may cause dementia-like symptoms [15, 16]. In addition, Lewy body pathology of the cardiac conduction system might result in arrhythmia, as alpha-synuclein deposits are present in cardiac nerves and the sinus node [17, 18]. A recent clinicopathological study found that 5.2% of individuals with LBD had SSS [19], compared to a prevalence of 0.17% in the general age-matched population [20]. Pacemaker implantation is a common management option to reduce associated symptoms of SSS [15].

In addition, cholinesterase inhibitors, which are widely used to treat dementia (including in people with DLB), are associated with an increased risk of bradycardia, syncope, falls, and

requiring a pacemaker implant [21, 22]. These drugs may also aggravate tendencies towards bradycardia in people with pre-existing SSS or heart block [23]. However, treatment with these drugs may be essential to improve cognitive and daily function, which might necessitate a pacemaker implant if bradyarrhythmia occurs [23].

Pacemaker implants to manage bradyarrhythmia may be associated with improved cognitive performance [24–27]. A previous diagnosis of dementia may need to be reassessed following a pacemaker implant [27]. However, these studies have not explicitly involved people with DLB, and have not presented other clinical outcomes besides cognitive test results. Understanding the experiences of individuals with DLB after a pacemaker implant to manage concurrent bradyarrhythmia could improve current management approaches, especially since bradyarrhythmia might be part of the underlying disease process.

Therefore, the aim of the present study was to explore how people with DLB experience daily life following a pacemaker implant to manage associated symptoms of bradyarrhythmia. As DLB impacts the life of family carers, this study also aimed to explore how spouse carers experience daily life after their DLB-affected spouse receives a pacemaker.

The use of qualitative research has been highlighted as complementary to quantitative research, as it captures a more holistic picture of everyday life among people with DLB [28]. However, to our knowledge, only one prior qualitative study has explored first-hand experiences of people with DLB, and it concluded that active participation in interviews could be achieved despite cognitive decline [29].

METHODS

Study Design

A case study design was used to collect qualitative data regarding participants' lived experiences. Techniques used to enhance rigor are described in the Methods and Methodological considerations sections.

The present study was approved by the national ethics committee of Sweden (no. 2021-01765) and the regional Ethics Review Board of Scania, Sweden (no. 195-21), and was conducted in accordance with the Declaration of Helsinki and its later amendments. Participation was voluntary, and participants received written and verbal information regarding the study, and provided their documented informed consent to participate. Patients and their partners were aware that their data would be published open access, and that data could potentially be identifiable. Patients were aware that pseudonyms would be used.

Selection of Participants

Purposeful and criterion sampling was used. To be enrolled, each participant with DLB had to be (1) diagnosed with DLB according to the latest consensus criteria [8], (2) currently a patient at a memory clinic in southern Sweden, (3) implanted with a pacemaker to manage bradyarrhythmia, (4) able to consent to the study, and (5) Swedish-speaking. Inclusion criteria for spouse carers were to be (1) Swedish-speaking, and (2) living with their spouse with DLB.

Based on these inclusion criteria, the senior physician and co-author (EL) suggested two community-dwelling married men. Both couples lived at home in southern Sweden. Each participant had western European ancestry with Swedish as their native language.

Data Collection

Initial and follow-up interviews were conducted with each dyad face-to-face at the memory clinic where the men were patients. Two consecutive interviews, with different interviewers, were conducted with each couple to obtain a deeper understanding of their lives, and to increase credibility. Both participating couples took interest in the initial and follow-up interviews. During the interviews, free narration was encouraged.

Initial Interviews

Initial interviews were conducted by EL within 1–2 months following the men receiving a pacemaker implant. EL had prior knowledge of the men. Interviews were semi-structured and started with the question “Describe how life has been since you received your pacemaker?”. Open-ended questions were asked to explore experiences and perceptions relating to the aims. Initial interviews lasted for 11 and 17 min respectively. Interviews were audio-recorded and transcribed verbatim by EL, who condensed the verbatim transcripts to shorten them, while preserving their core meaning [30].

Follow-up Interviews

One year after a pacemaker was implanted, each couple conducted a follow-up interview with first-author IH, a junior physician, and a PhD student. Except for reading previous transcripts, IH had no prior knowledge of the participants. Interviews were semi-structured and used open-ended questions based on interview guides (see Supplementary Material), with topics raised by each couple during the initial interview. Each interview guide also included topics issued by the WHO International Classification of Functioning, Disability, and Health, which provided a framework for the descriptions of health and health-related issues [31]. Follow-up interviews lasted for 31 and 45 min, respectively. Interviews were audio-recorded and transcribed verbatim by IH. At times, one of the wives (assumed name Berit) answered questions by directly addressing her husband.

Clinical Global Impression of Change (CGI-C) was assessed for both men a year after pacemaker implantation as a quantitative instrument [32].

Data Analysis

Qualitative content analysis was conducted as described by Graneheim and Lundman to analyze and interpret data collected at the interviews [30]. Transcripts from all interviews were initially read separately multiple times by EL

and IH to get a sense of the big picture. To increase dependability, the authors then separately searched for meaning units, which were labeled with codes. These coded meaning units were relating to the aims, and were compared between the authors. The authors sorted various codes based on their differences and similarities, and reached a consensus on potential categories and subcategories. The authors held repeated peer briefings to further explore various aspects of obtained content from the transcripts, until no new categories appeared. Data were iteratively re-examined using insights that emerged during analysis, and a confirmatory content analysis was conducted by a third person, AB, specialized in qualitative research. For more details, see Supplementary Material.

NVivo software (release 1.4) was used to organize and manage the qualitative data collected. The analytical process was conducted in Swedish, the original language, to avoid losses of meaning while analyzing transcripts [33]. After the analytical process had been conducted, each category, subcategory, and quote was carefully translated to English by the authors, to avoid loss of meaning. Examples of meaning units with their codes, subcategories, and categories are shown in Table 1.

Participants

Assumed names are used throughout this report. The couples were Anders and Alice, and Bertil and Bodil. When initial interviews were conducted in 2020, both men (Anders and Bertil) were aged over 65 years, and both wives were aged over 60 years. Anders received his DLB diagnosis in 2018, while Bertil received his DLB diagnosis in 2015. Clinical features supportive of DLB of orthostatic hypotension, syncope, and repeated falls were described by both men. According to routine treatment regime for DLB, both men were prescribed cholinesterase inhibitors (rivastigmine) and memantine. None of the men had co-occurring Alzheimer pathology according to cerebrospinal fluid analysis.

In early 2020, both men conducted 24-h ambulatory blood pressure monitoring via the

Table 1 Examples of how findings were yielded from the analytical process, showing some of the meaning units that build up the subcategories and categories

| Meaning unit | Code | Subcategory | Category |
|---|-----------------------|-----------------------------|---|
| <i>Before last year during this time, or before I had the surgery (pacemaker), if I was riding my bike, I felt insecure. But that is not the case anymore</i> | Self-confidence | Losses of consciousness | Gaining control |
| <i>We now have a device at home that notifies the heart clinic if something happens with the pulse. Then they will call us</i> | Reassurance | Remote pacemaker monitoring | |
| <i>After I received it (pacemaker), I felt more awake, and many of my friends told me that I looked more awake. But now I am used to it, so I do not think about it</i> | Self-consciousness | Wakefulness | Maintaining a social life |
| <i>We went to Catrina and Carl for coffee, and that went really well. To be fair, you were tired and a bit strained, but you had not been used to walking such long distances</i> | Opportunities | Physical stamina | |
| <i>... I never feel well rested because my underlying condition (DLB) always makes me feel tired</i> | Hopelessness | Features of DLB | Being influenced by concurrent diseases |
| <i>At the start of the summer there was a lot of fainting, several times. You were hospitalized, and it turned out to be pneumonia</i> | Living in uncertainty | Symptoms of other diseases | |

memory clinic to assess blood pressure levels. Day and night monitoring showed that Anders had a heart rate < 60 beats per minute 80% of the time, and < 50 beats per minute 24% of the time. Bertil had a heart rate < 50 beats per minute 40% of the time.

Both men were referred to a heart clinic at a large hospital in southern Sweden, and both demonstrated signs of sinus bradycardia and chronotropic incompetence. Due to symptoms of pre-syncope and syncope, both men were subsequently diagnosed with SSS. Continuation of low-dose cholinesterase inhibitors was deemed necessary. No changes were made in antidepressants or dopaminergic or cardiovascular medications within the year. One month before their pacemaker was implanted, Anders and Bertil scored 30/30 and 18/30, respectively, on Mini mental state examination (MMSE), and 47 and 241 s, respectively, on Trail making test A.

Pacemaker

Each man received a dual-chamber rate-adaptive pacemaker with a closed loop sensor (DDD-CLS; Enitra8 DR-T; Biotronik, Germany). This pacing mode is intended to resemble physiological heart rate response to match metabolic demand by sensing changes in right ventricular impedance (which in turn correlates to variations in right ventricular inotropy) [34]. Cardioverter-defibrillators were not implanted.

Each pacemaker was implanted during early 2020. Anders recorded 66% pacing and Bertil recorded 94% pacing within the following year. Pacing was almost exclusively atrial. Neither peri- nor post-operative complications were recorded.

RESULTS

Three categories and six subcategories were identified depicting pivotal experiences among

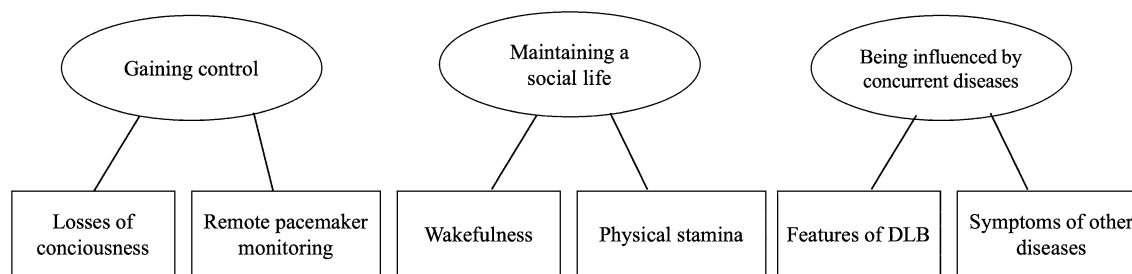


Fig. 1 Three categories and six subcategories identified from the study data

the participants within the year following the pacemaker implant (see Fig. 1). Categories were (1) *gaining control*, (2) *maintaining a social life*, and (3) *being influenced by concurrent diseases*. In the following account, categories and subcategories are presented. Clarifications of quotes are put in parentheses when necessary.

Clinical Global Impression of Change (CGI-C) was assessed as *minimally improved* for both men a year after pacemaker implantation compared to before.

Gaining Control

A pacemaker implant seemed to increase a sense of predictability and security during everyday situations, due to reduced syncope and an awareness of being remotely monitored by the heart clinic in case heart rate disturbances were unveiled. These factors seemingly resulted in a gain of control within the couples' daily lives.

Losses of Consciousness

A reduction of syncope was an important factor that was appreciated, not only by the men but also by their wives. Less syncope resulted in fewer falls, and was described as a way to avoid hurting oneself. Being able to recognize and manage syncope differently following the pacemaker implant was described by both couples, which appeared to increase their everyday predictability. While talking about syncope, Bodil said, with Bertil agreeing:

It has happened twice two weeks ago, but, besides that, there has been nothing... It might be that I was a bit stressed the

morning when it happened, so we might both have been stressed. I was going to a meeting at my workplace, I think it was a Monday. You were in the bathroom, so I had to help you. But you noticed it yourself because your knees felt weak, so you have not been alone while fainting. The second time you were walking, and your knees just felt weak. ... It happens much more rarely now. (Bodil, initial interview)

An increased sense of control enabled both men to take up joyful activities, such as bicycling and gardening, that had been difficult before their pacemaker implant. However, both couples indicated an underlying fear that syncope could still happen at any time, which seemed to result in precautions during daily activities. Both couples further described how a reduction of syncope had been transient during the year. Bertil and Bodil described how episodes of syncope had become increasingly abundant before the follow-up interview. Anders and Alice acknowledged a later shift towards increased dizziness and syncope. While talking about syncope, Anders said:

Before last year during this time, or before I had the surgery (pacemaker), if I was riding my bike, I felt insecure. But that is not the case anymore. I act carefully, because I know what can happen, but I feel more secure. ... I am not as dizzy as I was before. (Anders, follow-up interview)

Remote Pacemaker Monitoring

Both couples described how remote pacemaker monitoring could transmit heart rate

disturbances to the heart clinic in the event of sudden dizziness or syncope. This technique seemed to increase a sense of security, as a cause may be detected and communicated earlier by the heart clinic. While talking about dizziness and syncope, Alice said:

We now have a device at home that notifies the heart clinic if something happens with the pulse. Then they will call us. (Alice, follow-up interview)

Remote pacemaker monitoring also appeared to be reassuring, as it was described to detect heart rate disturbances, which might have otherwise gone unnoticed. During the initial interview, Bodil was reading text messages received from the heart clinic with registered heart rates from different everyday situations. She said:

We have something similar to a small mobile phone which should be placed on the bedside table to register the pulse. We can be gone for three days. When we come home it registers how it has been. (Bodil, initial interview)

According to the medical records frequent falls and syncope was reported before pacemaker implantation and none during the year after.

Maintaining a Social Life

This category reflects how certain physical and/or cognitive barriers seemed to have been mitigated within the year following the pacemaker implant. Mitigating these barriers facilitated abilities for each couple to maintain their social lives. Being able to maintain a social life was described as an integral part of each couple's well-being. In addition, all interviews were permeated by a sense of how the men were perceived by friends and family members in regard to physical and/or cognitive alterations, which suggested that the participants would sometimes confirm their own perceptions of improvements through others.

Wakefulness

Each couple agreed that the men had become more awake, which was mentioned in the context of feeling more lucid. Bertil described an increased will to do things, such as leaving home, and an ability to solve more difficult jigsaw puzzles than before. Anders described a sensation of sometimes “walking in a fog”, which appeared to reflect a clouded consciousness. He said:

I feel like I got a new life. I might feel a little more clear-headed. It might be because I am not tired, because then it is like you are always walking in a fog. (Anders, initial interview)

The couples described how the men would usually take on a reserved role in social settings due to difficulties with processing various impressions and keeping up with conversations. However, Bertil described himself as more talkative following his pacemaker implant, and both men described an increased awareness of their surroundings. Being able to engage in social interactions with friends and family seemed important for each couple. While talking about going to the gym, Alice said:

We go there (to the gym), and he goes there when he can. He tries. So that he has someone else he can talk to. It is a kind of social community and it is always the same people who are there. (Alice, follow-up interview while Anders was visiting the bathroom)

Anders mentioned how increased wakefulness had also been noticed by his friends, which indicated an importance of how he would be perceived by others. He said:

After I received it (pacemaker), I felt more awake, and many of my friends told me that I looked more awake. But now I am used to it, so I do not think about it. (Anders, follow-up interview)

Physical Stamina

Anders had relatively well-preserved physical abilities before the pacemaker surgery, and was not as affected by motor symptoms as Bertil. Anders and Alice neither describe any manifest nor latent physical alterations following his pacemaker implant. Bertil and Berit described difficulties to access social settings due to parkinsonism, which seemed to be a cause of social constraint. Following his pacemaker implant, the couple agreed that Bertil's physical stamina had improved while he was walking with his companion or wife within their community. Bertil said:

It has been a little better ... My legs don't feel as heavy. (**Bertil**, follow-up interview)

Bodil mentioned how the couple tried to create new social interactions. Being able to sustain prolonged physical effort was described to increase their ability to access outdoor activities with locals. The couple also described how they could now walk to meet their friends, which appeared to have been a major achievement for them. Bodil also mentioned how their companion had noticed a difference. She said:

The difference that the companion and I notice, is that there are good and bad days in your disease (DLB). But you have more energy without getting out of breath and without getting exhausted in the same way as before. Previously you had to put in more effort, you moaned and groaned. ... Shortly after you received your pacemaker we went out for a long walk. We went to Catrina and Carl for coffee, and that went really well. To be fair, you were tired and a bit strained, but you had not been used to walking such long distances. (**Bodil**, follow-up interview)

Being Influenced by Concurrent Diseases

All participants described how various symptoms continuously affected the men's health during the year, which seemingly resulted in worries within the daily lives of both couples. The couples either assigned symptoms as

features of DLB or concurrent diseases. However, sometimes it was difficult for the couples to determine causes and consequences associated with emerging or deteriorating symptoms, which appeared to have been a further cause of concern.

Features of DLB

Both men were well aware of their DLB diagnosis, and all participants implied a sense of not knowing what to expect during their daily routines in regard to fluctuations in attention and alertness as a core feature of DLB. Bertil and Bodil described how they sometimes needed to use a wheelchair to assist Bertil to get up in the morning, while he could sometimes get up entirely by himself. Such uncertain alterations subsequently seemed to result in distress for the couple, with Bertil concluding:

It is back and forth all the time. Every day is different. (**Bertil**, follow-up interview)

Difficulties in navigating among different core features of DLB also appeared to have been a cause of distress for the couple. While talking about walking outdoors, Bodil said:

Your gait worsened. I mean something happened with the Parkinson's, because your gait became worse. If it is due to Parkinson's or tiredness is difficult to know. (**Bodil**, follow-up interview)

While reflecting on their daily life, Anders and Alice would seemingly imply a sense of frustration in regard to alterations in alertness. Furthermore, these alterations seemed to result in feelings of hopelessness. Anders said:

I am worthless, I cannot fall asleep. I lay awake, tonight it was probably until one o'clock, other times it can probably be until either two or half past two. Yesterday at seven I was so tired that I felt nauseous. When I went to read at eight or nine, I felt awake. I do not know if it has to do with that. However, my sleep is not good. ... I never feel well rested because my underlying condition (DLB) always makes me feel tired. (**Anders**, follow-up interview)

Symptoms of Other Diseases

All interviews were permeated by portrayals of how the men's health had continuously been affected by various diseases besides DLB. Difficulties in navigating among sometimes interplaying disease trajectories seemed to result in further concern for the couples. At the initial interview, Bertil and Bodil mentioned how even the smallest infection might suddenly influence alertness, which indicated a sense of uncertainty within their life. A similar sense of uncertainty was implied while the couple was talking about syncope. Bodil said:

At the start of the summer there was a lot of fainting, several times. You were hospitalized, and it turned out to be pneumonia. We did not know because you were feeling very low. (**Bodil**, follow-up interview)

In addition, both couples described how managing of one symptom sometimes caused deterioration of another. Anders described how it had been difficult to manage symptoms of various diseases besides DLB, and further expressed how life sometimes felt meaningless in regard to not getting better. With a sense of dejection, Alice concluded:

He is sweating heavily. We notice a connection between his medicine (against depression) and these tremendous bouts of sweating. Ultimately, he does not want to go out. ... I don't think that he feels well mentally, because the physical (back pain), sweating and so forth affects the whole a lot. (**Alice**, follow-up interview, while Anders was visiting the bathroom)

DISCUSSION

The present study provided a qualitative approach to describe how two men with DLB and their spouses experienced daily life, focusing on functioning and health following a pacemaker implant to manage concurrent SSS. Present findings indicate how the pacemaker implant led to a gain of control within the couples' daily lives in regard to less syncope/

fewer falls and remote pacemaker monitoring. Our findings also indicate how perceived physical and/or cognitive improvements influenced how the couples maintained their social lives. Furthermore, our findings demonstrate how living with several, and sometimes interplaying, concurrent disease continuously affected their daily lives.

Gaining Control

A reduction of syncope and falls seemed to increase a sense of security within the couples' daily lives. Larsson et al. addressed similar first-hand experiences of how fear of falling influenced people with DLB. In their qualitative study, fear of falling was described as resulting in precautions such as moving slower and refraining from leaving home, ultimately reducing quality of life. However, fear of falling was not described in relation to syncope, but rather due to deterioration of overall motor functions [29]. Furthermore, Armstrong et al. interviewed former family carers of people with DLB. They described how hospitalization after falls sometimes caused overall health deterioration associated with unpredictable disease trajectories [35].

A small randomized cross-over study by Sahul et al. showed neither hemodynamic nor symptomatic differences in elderly people with orthostatic hypotension due to autonomic dysfunction, with or without dual-chamber (DDD) cardiac pacing switched on. In their study, five of six patients involved experienced syncope or pre-syncope regardless of cardiac pacing or not, and included five patients with assumed LBD [36].

In the present study, both men received dual-chamber rate-adaptive pacemakers with a closed loop sensor (DDD-CLS). Abi-Samra et al. showed a reduced prevalence of orthostatic hypotension among orthostatic patients with DDD-CLS after 1 min of standing compared with DDD paced controls. However, associated orthostatic symptoms were not evaluated [37]. Furthermore, several randomized control trials have demonstrated that DDD-CLS is superior to dual-chamber paced controls (CLS mode

switched off) in preventing syncope and pre-syncope episodes among patients with recurrent cardioinhibitory vasovagal syncope [38–42]. In addition, Occhetta et al. also found increased quality of life scores among DDD-CLS patients at 1-year follow-up, compared with dual-chamber paced controls [38]. However, none of these studies have specified any involvement of participants with neither assumed underlying Lewy body pathology nor cognitive impairment.

In our present study, the men described how dizziness and/or syncope and falls were still present following their pacemaker implant, although to a lesser extent. The perceived continuation of these symptoms might have been due to orthostatic hypotension as a feature of DLB, while the perceived decrease of these symptoms might have been due to each pacemaker suppressing symptoms of SSS and/or improving homeostatic cardiovascular feedback functions through CLS. The perceived return of these symptoms within a year might have been due to progression of autonomic dysfunction. Conversely, a longitudinal study by Cummings et al. showed limited accuracy of elderly people to recall falls, and that inaccuracy was further affected by cognitive decline [43].

Furthermore, remote pacemaker monitoring was described as reassuring by both couples. Ploux et al. reported that remote pacemaker monitoring provides earlier detection of sudden arrhythmic events than in-hospital rhythm evaluations only. They reported that earlier arrhythmia detection makes it easier to recall certain activities that might have triggered an alarm. Furthermore, they reported that remote monitoring reduces the risk of all-cause hospitalization [44]. However, this monitoring technique is not intended as an immediate alarm system, and a qualitative study by Fraiche et al. described how pacemaker carriers might view the technique as a 24-h safety system [45]. Therefore, our findings suggest that the participants relied too heavily on this technique, which could have created a false sense of security.

Maintaining a Social Life

Maintaining a social life seemed important for the well-being of each couple. A need among people with DLB and family carers to maintain an active social life has previously been reported after both qualitative and quantitative research [29, 46, 47]. In accordance with our findings, both cognitive and physical barriers have been reported to result in social constraint and reduced quality of life for both family carers and people living with DLB [28]. A quantitative descriptive study by Park et al. found how family carers of people with DLB were creative in building social networks, which was also reflected in our findings. They further reported how this would sometimes become increasingly difficult as disease progressed [48].

In the present study, each couple agreed that the men felt more awake following their pacemaker implant, which was described in the context of perceived cognitive improvements. Koide et al. found that severe bradycardia correlated with reduced cerebral blood flow, and that subsequent implanting of a pacemaker was associated with improved cognitive performance using the Wechsler memory scale, suggesting that heart rate is an important factor for cerebral circulation [25]. Martis et al. found increased MMSE score and improved Trail making test A time among people with bradyarrhythmia following a pacemaker implant [26]. Barbe et al. compared cognitive functions of people receiving a first pacemaker implant with people undergoing a replacement implant to manage bradyarrhythmia. They found improvements in cognition associated with the first-time pacemaker implant correlates with increased heart rate. In addition, they found that cognitive improvements on the Wechsler memory scale and MMSE progressed during a 6-month follow-up [27]. Three of three included patients with dementia who underwent a first implant later had their dementia diagnosis reassessed to either mild cognitive impairment or normalized cognitive performance within 6 months [27]. In contrast, Rockwood et al. found no cognitive improvements at 6 and 12 months following a first-time or replacement pacemaker implant, despite subjective

impressions of improvement [24]. Therefore, the perceived increased wakefulness of the men in the present study might have been solely subjective. Furthermore, the patients received pacemakers at different time points in their disease which might have influenced their experiences and their possibilities to communicate them.

One couple (Bertil and Bodil) described how gains in physical stamina influenced their ability to access and maintain social interactions. Larsson et al. reported how increased physical needs were associated with feelings of being a burden in social contexts, resulting in reduced attendance at social events by people with DLB [29]. A randomized cross-over trial by Coenen et al. found increased 6-min walking distance by patients with chronotropic incompetence when comparing DDD-CLS pacing and non-rate-adaptive DDD pacing [49]. Abi-Samra et al. reported that DDD-CLS was beneficial during low-energy daily physical activity when comparing DDD-CLS to DDD paced controls, of whom a majority were patients who received a pacemaker to manage SSS. However, their 6-min walking distance was not improved [37].

Being Influenced by Concurrent Diseases

Living with concurrent diseases seemed to continuously have influenced the lives of the participants during the year following the pacemaker implant. Consistent with previous findings by others, each couple described worries relating to both features DLB and symptoms of other diseases [28]. Bentley et al. described that an increased awareness of how to manage different symptoms and tailored interventions may be a way to increase the support for people with DLB and the family carers [28].

Consistent with our findings, Taylor et al. described the complexity of living with DLB, and that management of one symptom may result in deterioration of another [50]. They found that symptoms may be expressed variably over time due to the clinical core feature of fluctuations, which is also reflected by the present findings. Previous qualitative studies of either family carers or people with DLB have

mostly used cross-sectional designs to determine factors associated with aspects of living with DLB, and have described that such designs might affect understanding of changes over time [28, 29].

Methodological Considerations and Limitations

The generalizability of our findings is reduced by only including Swedish-speaking couples, and because the participants with DLB are of only one sex. However, as the authors are native Swedish speakers, it was deemed more suitable to include Swedish-speaking couples only to avoid misinterpretations during the interviews. However, the men's differences in cognitive and physical functions were deemed to have increased generalizability. Even though the sample size was small, the many views expressed by the participants were homogenous.

To make the setting more relaxed, interviews took place in conference rooms and not medical examination rooms. There were no medical appointments before or after the interviews, and the couples had been informed of this beforehand. Interviewers were casually dressed to further relax the setting. The use of conference rooms provided a certain distance, which made it possible to refrain from using personal protective equipment to reduce the possibility of COVID-19 spread. Because of the COVID-19 pandemic, it was deemed unsuitable to conduct interviews at participants' homes, which would otherwise have been ideal to increase credibility. Furthermore, the pandemic was mentioned by the couples to impact the ability to visit their grandchildren at home, but was not portrayed as a barrier to social activities outdoors or gatherings with people of the same age indoors.

As reflected by the quotes, one couple consisted of the man (Anders) speaking more than his wife, and the other couple of the wife (Bodil) speaking more than her husband. However, the quieter person often agreed or disagreed with statements expressed by their partner, and each couple had several discussions among themselves during the interviews. Additional time

was provided by the interviewer for the quieter man (Bertil) to think and reflect on his experiences, which in turn resulted in more active participation.

EL did have prior knowledge of the couples, which might have influenced their openness during the initial interview. However, prolonged engagement was seen as important to gain a better understanding of the participants' everyday lives to increase credibility. Each couple expressed similar experiences during the initial and follow-up interviews. Follow-up interviews were conducted by IH, who had neither met nor spoken with the couples prior to interviewing them. During all interviews, each participant expressed negative perceptions, indicating that they felt free to express their views. However, it is difficult to know if participants felt fully free to share their experiences with their significant other. The men might have been worried to be perceived as being burdens by their wives, and the wives might have felt that they were intruding on their husband's autonomy.

The use of consecutive interviews, with investigator triangulation, was used to increase credibility, assess consistency, and address longitudinal experiences. The period before the follow-up interview might have resulted in recall bias. However, by interviewing dyads, participants were able to discuss with their spouse how, when, and where different situations had played out.

Quantitative measurements were not conducted systematically before and after pacemaker implantation due to the qualitative aim of the study. For example, we chose not to use a mixed methods design, as we aimed to focus on lived experiences and patient perspectives.

Furthermore, co-occurrence of SSS in the men might not be due to underlying Lewy body pathology, and this study does not imply that DLB alone should be regarded as an indication for receiving a pacemaker implant.

CONCLUSION

If people with DLB present with syncope, falls, and/or bradycardia, the presence of concurrent

bradyarrhythmia should be assessed, and receiving a subsequent pacemaker implant could enhance day-to-day functioning and health by relieving mimicking features of DLB.

Present findings highlight the complexity and dynamic trajectory of DLB, which could decrease the validity of cross-sectional quantitative research and make it difficult to evaluate management strategies over time using longitudinal qualitative study designs.

This study provides an incentive to further investigate the co-occurrence of bradyarrhythmia in DLB, and potential influences of a pacemaker implant on daily life of people with DLB and their family carers. Such studies could use a mixed-methods design by assessing cognitive performance and hemodynamic functions in a longitudinal study besides qualitative follow-up interviews.

ACKNOWLEDGEMENTS

We would like to thank the participants of the study.

Funding. The journal's fee was funded by the Trolle-Wachtmeister Foundation for Medical Research and the Kock Foundation for Medical Research. The work was supported by the Swedish Federal governmental under the ALF agreement.

Author Contributions. Elisabet Londos and Isak Heyman designed the study, conducted the interviews, collected demographics data, and performed the main data analysis. Annika Brorsson provided a confirmatory data analysis, and substantially revised the work. Torbjörn Persson provided essential experience regarding relevant pacemaker modes and reference applicability, and substantially revised the work. All authors approved the final manuscript.

Prior presentation. The abstract of this manuscript was presented as an on-site poster and e-poster at the AD/PD 2023 Alzheimer's and Parkinson's Disease Conference in Gothenburg, Sweden between 28th March and 1st April 2023.

Disclosures. Isak Heyman, Annika Brorsson, Torbjörn Persson and Elisabet Londos declare that they have no competing interests.

Compliance with Ethics Guidelines. The present study was approved by the national ethics committee of Sweden (no. 2021-01765) and the regional Ethics Review Board of Scania, Sweden (no. 195-21) and was conducted in accordance with the Declaration of Helsinki and its later amendments. Participation was voluntary, and participants received written and verbal information regarding the study and provided their documented informed consent to participate. Patients and their partners were aware that their data would be published open access and that data could potentially be identifiable. Patients were aware that pseudonyms would be used.

Data Availability. A fully anonymized version of the dataset used and analysed during this study is available from the corresponding author on reasonable request.

Open Access. This article is licensed under a Creative Commons Attribution-Non-Commercial 4.0 International License, which permits any non-commercial use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc/4.0/>.

REFERENCES

1. Vann Jones SA, O'Brien JT. The prevalence and incidence of dementia with Lewy bodies: a systematic review of population and clinical studies. *Psychol Med.* 2014;44(4):673–83.
2. Savica R, Boeve BF, Mielke MM. When Do α -Synucleinopathies Start? An Epidemiological Timeline: A Review. *JAMA Neurol.* 2018;75(4):503–9.
3. Boström F, Jönsson L, Minthon L, Londos E. Patients with dementia with lewy bodies have more impaired quality of life than patients with Alzheimer disease. *Alzheimer Dis Assoc Disord.* 2007;21(2):150–4.
4. Ricci M, Guidoni SV, Sepe-Monti M, et al. Clinical findings, functional abilities and caregiver distress in the early stage of dementia with Lewy bodies (DLB) and Alzheimer's disease (AD). *Arch Gerontol Geriatr.* 2009;49(2):e101–4.
5. Svendsboe E, Terum T, Testad I, et al. Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer's disease. *Int J Geriatr Psychiatry.* 2016;31(9):1075–83.
6. van de Beek M, van Steenoven I, Ramakers I, et al. Trajectories and determinants of quality of life in dementia with Lewy bodies and Alzheimer's disease. *J Alzheimers Dis.* 2019;70(2):389–97.
7. Ballard CG, Shaw F, Lowery K, McKeith I, Kenny R. The prevalence, assessment and associations of falls in dementia with Lewy bodies and Alzheimer's disease. *Dement Geriatr Cogn Disord.* 1999;10(2):97–103.
8. McKeith IG, Boeve BF, Dickson DW, et al. Diagnosis and management of dementia with Lewy bodies: fourth consensus report of the DLB Consortium. *Neurology.* 2017;89(1):88–100.
9. Spears CC, Besharat A, Monari EH, Martinez-Ramirez D, Almeida L, Armstrong MJ. Causes and outcomes of hospitalization in Lewy body dementia: a retrospective cohort study. *Parkinsonism Relat Disord.* 2019;64:106–11.
10. Lee CY, Cheng SJ, Lin HC, Liao YL, Chen PH. Quality of life in patients with dementia with Lewy bodies. *Behav Neurol.* 2018;2018:8320901.
11. Yamamoto T, Tamura N, Kinoshita S, et al. A case of sick sinus syndrome and autonomic failure with Parkinson's disease. *Auton Neurosci.* 2009;146(1–2):115–7.
12. Adamec I, Klepac N, Milivojević I, Radić B, Habek M. Sick sinus syndrome and orthostatic

- hypotension in Parkinson's disease. *Acta Neurol Belg.* 2012;112(3):295–7.
13. Olshansky B, Feigofsky S, Cannom DS. Is it bradycardia or something else causing symptoms? *HeartRhythm Case Rep.* 2018;4(12):601–3.
 14. Sawagashira R, Sasagawa Y, Matsukura M, Takamaru Y. Sick sinus syndrome mimicking autonomic dysfunction of dementia with Lewy bodies. *Cureus.* 2021;13(4): e14667.
 15. Adán V, Crown LA. Diagnosis and treatment of sick sinus syndrome. *Am Fam Phys.* 2003;67(8): 1725–32.
 16. Kashou AH, Goyal A, Nguyen T, Chhabra L. Atrioventricular block. StatPearls. Treasure Island (FL): StatPearls Publishing Copyright © 2022, StatPearls Publishing LLC.; 2022.
 17. Okada Y, Ito Y, Aida J, Yasuhara M, Ohkawa S, Hirokawa K. Lewy bodies in the sinoatrial nodal ganglion: clinicopathological studies. *Pathol Int.* 2004;54(9):682–7.
 18. Tábuas-Pereira M, Durães J, Beato-Coelho J, et al. Lewy body dementia is associated with an increased risk of atrial fibrillation: a case–control study. *J Clin Neurosci.* 2022;99:62–5.
 19. Javanshiri K, Drakenberg T, Haglund M, Englund E. Sudden cardiac death in synucleinopathies. *J Neuropathol Exp Neurol.* 2023;82(3):242–9.
 20. Dakkak W, Doukky R. Sick sinus syndrome. StatPearls. Treasure Island (FL): StatPearls Publishing Copyright © 2023, StatPearls Publishing LLC.; 2023.
 21. Gill SS, Anderson GM, Fischer HD, et al. Syncope and its consequences in patients with dementia receiving cholinesterase inhibitors: a population-based cohort study. *Arch Intern Med.* 2009;169(9): 867–73.
 22. Hernandez RK, Farwell W, Cantor MD, Lawler EV. Cholinesterase inhibitors and incidence of bradycardia in patients with dementia in the Veterans affairs new England healthcare system. *J Am Geriatr Soc.* 2009;57(11):1997–2003.
 23. Young S, Chung E, Chen MA. Cardiovascular complications of acetylcholinesterase inhibitors in patients with Alzheimer's disease: a narrative review. *Ann Geriatr Med Res.* 2021;25(3):170–7.
 24. Rockwood K, Dobbs AR, Rule BG, Howlett SE, Black WR. The impact of pacemaker implantation on cognitive functioning in elderly patients. *J Am Geriatr Soc.* 1992;40(2):142–6.
 25. Koide H, Kobayashi S, Kitani M, Tsunematsu T, Nakazawa Y. Improvement of cerebral blood flow and cognitive function following pacemaker implantation in patients with bradycardia. *Gerontology.* 1994;40(5):279–85.
 26. Martis A, Gusetu G, Cismaru G, Zdrenghia D, Leucuta DC, Pop D. Improvement of cognitive function and interleukin 1 beta serum concentrations following cardiac pacemaker implantation in patients with symptomatic bradycardia. *J Pers Med.* 2021;11(8):770.
 27. Barbe C, Puisieux F, Jansen I, et al. Improvement of cognitive function after pacemaker implantation in very old persons with bradycardia. *J Am Geriatr Soc.* 2002;50(4):778–80.
 28. Bentley A, Morgan T, Salifu Y, Walshe C. Exploring the experiences of living with Lewy body dementia: an integrative review. *J Adv Nurs.* 2021;77(12): 4632–45.
 29. Larsson V, Holmbom-Larsen A, Torisson G, Strandberg EL, Londos E. Living with dementia with Lewy bodies: an interpretative phenomenological analysis. *BMJ Open.* 2019;9(1): e024983.
 30. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today.* 2004;24(2):105–12.
 31. International Classification of Functioning, Disability, and Health : ICF. Version 1.0. Geneva : World Health Organization, [2001] ©2001; 2001.
 32. Busner J, Targum SD. The clinical global impressions scale: applying a research tool in clinical practice. *Psychiatry (Edgmont).* 2007;4(7):28–37.
 33. van Nes F, Abma T, Jonsson H, Deeg D. Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing.* 2010;7(4):313–6.
 34. Tomaino M, Russo V, Giacobelli D, Gargaro A, Brignole M. Cardiac Pacing in cardioinhibitory reflex syncope: clinical use of closed-loop stimulation. *Arrhythm Electrophysiol Rev.* 2021;10(4): 244–9.
 35. Armstrong MJ, Alliance S, Taylor A, Corsentino P, Galvin JE. End-of-life experiences in dementia with Lewy bodies: qualitative interviews with former caregivers. *PLoS ONE.* 2019;14(5): e0217039.
 36. Sahul ZH, Trusty JM, Erickson M, Low PA, Shen WK. Pacing does not improve hypotension in patients with severe orthostatic hypotension—a prospective randomized cross-over pilot study. *Clin Auton Res.* 2004;14(4):255–8.

37. Abi-Samra FM, Singh N, Rosin BL, Dwyer JV, Miller CD. Effect of rate-adaptive pacing on performance and physiological parameters during activities of daily living in the elderly: results from the CLEAR (Cynos Responds with Physiologic Rate Changes during Daily Activities) study. *Europace*. 2013;15(6):849–56.
38. Occhetta E, Bortnik M, Audoglio R, Vassanelli C. Closed loop stimulation in prevention of vasovagal syncope. Inotropy Controlled Pacing in Vasovagal Syncope (INVASY): a multicentre randomized, single blind, controlled study. *Europace*. 2004;6(6):538–47.
39. Russo V, Rago A, Papa AA, et al. The effect of dual-chamber closed-loop stimulation on syncope recurrence in healthy patients with tilt-induced vasovagal cardioinhibitory syncope: a prospective, randomised, single-blind, crossover study. *Heart*. 2013;99(21):1609–13.
40. Palmisano P, Dell’Era G, Russo V, et al. Effects of closed-loop stimulation vs. DDD pacing on haemodynamic variations and occurrence of syncope induced by head-up tilt test in older patients with refractory cardioinhibitory vasovagal syncope: the Tilt test-Induced REsponse in Closed-loop Stimulation multicentre, prospective, single blind, randomized study. *Europace*. 2018;20(5):859–66.
41. Baron-Esquivias G, Morillo CA, Moya-Mitjans A, et al. Dual-chamber pacing with closed loop stimulation in recurrent reflex vasovagal syncope: the SPAIN study. *J Am Coll Cardiol*. 2017;70(14):1720–8.
42. Brignole M, Russo V, Arabia F, et al. Cardiac pacing in severe recurrent reflex syncope and tilt-induced asystole. *Eur Heart J*. 2021;42(5):508–16.
43. Cummings SR, Nevitt MC, Kidd S. Forgetting falls. The limited accuracy of recall of falls in the elderly. *J Am Geriatr Soc*. 1988;36(7):613–6.
44. Ploux S, Strik M, Varma N, Eschalier R, Bordachar P. Remote monitoring of pacemakers. *Arch Cardiovasc Dis*. 2021;114(8–9):588–97.
45. Fraiche AM, Matlock DD, Gabriel W, Rapley FA, Kramer DB. Patient and provider perspectives on remote monitoring of pacemakers and implantable cardioverter-defibrillators. *Am J Cardiol*. 2021;149:42–6.
46. Vatter S, McDonald KR, Stanmore E, Clare L, Leroi I. Multidimensional care burden in Parkinson-related dementia. *J Geriatr Psychiatry Neurol*. 2018;31(6):319–28.
47. Vatter S, Stanmore E, Clare L, McDonald KR, McCormick SA, Leroi I. Care burden and mental ill health in spouses of people with Parkinson disease dementia and Lewy body dementia. *J Geriatr Psychiatry Neurol*. 2020;33(1):3–14.
48. Park J, Tolea M, Arcay V, Lopes Y, Galvin J. Self-efficacy and social support for psychological well-being of family caregivers of care recipients with dementia with Lewy bodies, Parkinson’s disease dementia, or Alzheimer’s disease. *Soc Work Ment Health*. 2018;17:1–26.
49. Coenen M, Malinowski K, Spitzer W, et al. Closed loop stimulation and accelerometer-based rate adaptation: results of the PROVIDE study. *Europace*. 2008;10(3):327–33.
50. Taylor JP, McKeith IG, Burn DJ, et al. New evidence on the management of Lewy body dementia. *Lancet Neurol*. 2020;19(2):157–69.