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Incorporating a Picture-Based Book Into Routine Care for People With Epilepsy and Intellectual Disabilities: Perspectives From Patients, Carers and Clinicians

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ABSTRACT

Background: People with intellectual disabilities are more likely to experience epilepsy than the general population, negatively affecting their quality of life. Accessible and personalised resources may support epilepsy management. This study explores patients', carers' and clinicians' perspectives on using a picture-based book to support epilepsy care in a clinical consultation.

Methods: Eighteen adults with intellectual disabilities and epilepsy took part in an interview 4-weeks after they had used the Beyond Words 'Getting on with epilepsy' book with a clinician. In 13 of these interviews, carers also took part. Five clinicians involved in book use also took part in interviews. Reflexive thematic analysis was used.

Findings: Book use extended people's understanding of epilepsy, reducing anxiety and increasing confidence. Before using the book, clinicians needed to be familiar with the book's content, how to use the book and the patients' background and preferences. The book was felt to support epilepsy care in a routine service context, and participants highlighted when and how the book may be best targeted for maximum benefit.

Conclusions: Use of a picture-based book can provide accessible and tailored information to support epilepsy care for people with intellectual disabilities. It was felt to be feasible to use in routine clinical care, and may also be beneficial in home and social care settings.

1 | Introduction

Individuals with intellectual disability are more likely to experience epilepsy than the general population, with prevalence rates of 22% (Robertson et al. 2015) compared with 0.8% (Fiest et al. 2017). As seizures are also more likely to be complex, frequent and resistant to medication, epilepsy can restrict everyday life, have negative impacts on quality of life and be challenging to manage for people with intellectual disabilities (McGrother et al. 2006; Mengoni et al. 2016; Sun et al. 2022).

National Institute for Health and Care and Excellence (NICE 2022) guidelines in England highlight that tailored information should be provided to people with epilepsy, and it

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Summary

- People with learning disabilities and epilepsy do not always receive information that is easy to understand
- Doctors and nurses used a book with pictures called 'Getting on with epilepsy' with people with learning disabilities and epilepsy
- We asked doctors, nurses, people with learning disabilities and their carers what they thought about the book
- The book helped people to understand their epilepsy and feel less worried about it
- People thought that book should be used in the NHS
- Doctors and nurses should have training so they know how best to use the book

is also recommended that clinicians discuss safety issues, lifestyle, medication and wellbeing, and support people to make informed decisions about their care. For people with intellectual disabilities, reasonable adjustments and adaptations should be made, including providing accessible information, scheduling appointments at the best time for the individual and with a support person they choose and having longer appointments (Kerr et al. 2023). However, people with intellectual disabilities and their carers often report a lack of information and support tailored to their needs (Mengoni et al. 2016; Thompson et al. 2013).

A potential reasonable adjustment to epilepsy care is the use of the 'Getting on with epilepsy' book published by Beyond Words (Hollins et al. 2014). This book uses pictures to tell the story of a young man who experiences seizures, including images of him having a seizure, going to the doctor, having diagnostic tests, taking medication and going out with friends. There are 54 pictures in total, and there are no words accompanying the pictures, although there is a written (suggested) storyline included after the pictures. Beyond Words publish a range of picture-based books on different topics, and they are recommended to support communication and discussions for people who may find reading difficult (Hollins et al. 2017). Key to reading a Beyond Words book is the emphasis on facilitating the patient to tell the story and share their interpretation (Hollins et al. 2017). A layered reading approach is recommended, which prioritises open-ended questions to support the reader's interpretation of the pictures. In consultations, this can support clinicians to explore what the patient has understood and to gain insight into their experiences and feelings (Boardman et al. 2014; Hollins et al. 2017).

There has been limited research to evaluate such picture-based books. Tuffrey-Wijne et al. (2006) focused on the Beyond Words 'Getting on with Cancer' book and found that people with intellectual disabilities had a clear need for cancer information, which they felt the book could help address. The book also helped participants talk about their own cancer experiences. Wythe et al. (2024) explored views on a newly developed Beyond Words book about COVID-19 vaccinations, and found that this may facilitate personalised conversations between people with intellectual disabilities and their carers.

The WIELD feasibility randomised controlled trial showed that it was possible to use 'Getting on with epilepsy' as an intervention with people with intellectual disabilities and epilepsy, and there was preliminary evidence of a benefit on quality of life (Mengoni et al. 2016). In this study, a research nurse used the 'Getting on with epilepsy' book with the intervention group, who then took the book home to use for 20 weeks, and this was compared to treatment as usual. The present study draws on data from WIELD 2, a follow-on study that trained clinicians involved in patients' routine care to use the book and video-recorded the intervention sessions to understand key features of book use (Mengoni et al. 2024). Clinicians received face-to-face training, including role-play scenarios, with an emphasis on using open prompts rather than questions aimed at gathering information, as may often be the case in clinical consultations. WIELD 2 found that patients and clinicians worked together to construct a narrative relating to the book, and that this prompted clinically useful discussions about patients' experience of epilepsy and its management. There were some differences in the clinicians' approach in the intervention sessions compared to the layered reading approach recommended by Beyond Words. For example, clinicians sometimes used prompts to 'correct' patients' understanding of the book, particularly where clinically-relevant information was being discussed.

The present study draws on data from WIELD 2 and focuses on the views of patients, carers and clinicians. The study's aim was to explore if and how the book should be used in routine care, with the intention of informing potential implementation in healthcare settings.

2 | Methods

The full methods for WIELD 2 are reported elsewhere (Mengoni et al. 2024). Here, we focus on the elements relating to the semi-structured interviews.

2.1 | Design

WIELD 2 involved a single intervention session when clinicians and patients used the 'Getting on with epilepsy book' together. After a 4-week period, semi-structured interviews took place with patients. Some carers took part in this interview but may not have been present in the intervention session. Clinicians were interviewed after they had finished delivering the intervention to all patients.

The present study focuses on the interviews with patients, carers and clinicians, which were analysed using reflexive thematic analysis (Braun and Clarke 2006, 2022). An inductive experiential approach was used to centre the views and experiences of the participants and draw shared meaning across the different groups of participants, that is, patients, carers and clinicians.

2.2 | Participants and Recruitment

For clarity, we use the following terms to refer to the different groups of participants who took part in interviews: 'patients,' that is, adults with intellectual disabilities and epilepsy, 'carers,' that is, people who took part in interviews with patients and 'clinicians,' that is, doctors and nurses who delivered the intervention.

Recruitment took place in two NHS Trusts in the East of England, Hertfordshire Partnership University NHS Foundation Trust (HPFT) and Norfolk Community Health and Care (NCH&C), from May 2019 to Feb 2020. To be eligible, patients had to: have an intellectual disability, be under the care of epilepsy services, have experienced at least one epileptic seizure in the last year and have the capacity to consent to the study. Patients were initially approached via NHS staff. The research team then contacted patients who were interested in the study to discuss this further and obtain consent.

If a carer was present with the patient at the interview, then we asked the patient if they would like the carer to support them through the interview and contribute where appropriate. If so, then we invited the carer to read an information sheet and complete a consent form.

Clinicians involved in recruitment and intervention delivery were also invited to take part in interviews.

2.3 | Data Collection

2.3.1 | Demographics Questionnaire

Patients answered questions about their demographics and epilepsy history (Table 1) before the intervention.

2.3.2 | Patient and Carer Interviews

Patient and carer interviews took place at a research visit 4 weeks after the patient had used the 'Getting on with epilepsy book' with a clinician. During the 4-week intervening period, patients were asked to use the book at least two more times at home. The interviews were audio-recorded and had two parts: video elicitation and a semi-structured interview.

Video elicitation is used to support participants to reflect on their thoughts and feelings during a particular event (Henry and Fetters 2012). Before the interview, the researcher watched the video-recorded intervention session and identified up to five key points during the book reading and prepared open prompts; for example, a clip of when the participant related the image to something that had happened in their life, and a prompt may have been 'can you remember what you thought about this picture?' During the visit, the researcher showed the relevant clips on a laptop and used the prompts to facilitate discussion to gain a more in-depth understanding of how the book was used.

Following video elicitation, the researcher conducted a semi-structured interview with the patient, and carer if present. The interview included eliciting participant and carer views about the epilepsy book, including whether they felt it was beneficial or not and why, what it was like to use the book with a clinician and at home, and how it might best be used. Interview schedules were created, including an accessible version with simple questions and images.

TABLE 1 | Patient demographics.

	Mean (standard deviation)/Number of participants (%)
Age (years)	33.83 (16.65)
Gender	
Male	6 (33%)
Female	12 (67%)
Ethnicity	
White British	17 (94%)
Black Caribbean	1 (6%)
Home setting	
Supported accommodation/ group home	8 (44%)
Family home	8 (44%)
Tenancy	2 (12%)
Time since diagnosis (years)	24.89 (21.94)
Type of seizures	
Tonic clonic	15
Focal	7
Absences	2
Number of seizures in last month [a]	2.88 (3.10)
Severity of seizures in last month [b],[c]	2.46 (1.20)

[a] $n = 17$
[b] $n = 13$
[c] ranked 1–4, with 1 = very severe and 4 = mild

Due to COVID-19 restrictions, three interviews took place via telephone, and therefore, the video elicitation did not take place. All other research visits took place in the patient's home.

2.3.3 | Clinician Interviews

Clinicians took part in semi-structured interviews after they finished all their intervention sessions. Interviews were audio-recorded and consisted of video elicitation and a semi-structured interview.

The video elicitation approach and method were largely the same as for patients. Clips were drawn from across all patients that a clinician had worked with, and prompts also covered their perceptions about patients' thoughts and feelings, for example, 'what did you think the patient understood about that picture?'.

The semi-structured interview followed a topic guide exploring clinicians' experience of using the book with patients, perceived benefits and drawbacks of the book, and facilitators and barriers to book use in routine care.

Two interviews took place in person at the clinician's NHS Trust. Due to COVID-19 restrictions, three interviews took place remotely. Two of these were via video call, but due to technology issues, one of these interviews was via phone call, so we were unable to carry out the video elicitation. A clinician who had supported recruitment but did not personally deliver the intervention did not take part in video elicitation.

2.3.4 | Ethics

Ethical approval was granted by the South Central Oxford C NHS Research Ethics Committee (IRAS: 254590; REC reference number: 19/SC/0029), who allowed only people with capacity to consent to participate. Governance approval was granted by the Health Research Authority, the NHS Trusts involved and the University of Hertfordshire.

2.4 | Data Analysis

The video elicitations and interviews were professionally transcribed and thematically analysed on NVivo following Braun and Clarke's six-phase process (Braun and Clarke 2006, 2022): familiarisation with the data set; coding; generating initial themes; developing and reviewing themes; refining, defining and naming themes; writing up.

During the analysis, we actively considered that participants had different experiences of book use and that the context of participants' lives would impact their views. We also acknowledged that our own experiences and beliefs would affect the interpretation of the data. Through a critical realist lens, our aim was to embrace these complexities and produce a meaningful single account of the data, which incorporated the experiences and views of all our participants. We reflected on our personal and professional experiences through discussions and memo writing during the analysis process.

Two analysts (CHW and a postgraduate research assistant) coded interviews from patients and carers. RB coded the clinicians' interviews. Different analysts were used due to pragmatic reasons about staff availability. The initial coding was both descriptive (e.g., information about participant's epilepsy status) and latent (e.g., what may affect implementation in routine practice). All analysts coded independently but had regular discussions with SM to reflect on the coding and their initial themes. Two of the 23 transcripts were double-coded (9%).

As the initial analyses for the patient/carer and clinician interviews had significant similarities, these were merged into a final thematic analysis. The separate thematic structures and the transcripts were reviewed, and themes and subthemes were developed that synthesised meaning across the two datasets. This was undertaken by SM and LF.

3 | Results

Twenty patients took part in the overall WIELD 2 study, and of these, 18 took part in the post-intervention interview (Table 1). One person was unable to be contacted and one declined to take part in the interview. Thirteen carers took part in the interviews: seven family members and six support workers.

Two-thirds of the patients were female and the majority were White British. The mean age was 33 years, although there was a wide range, and most people had been diagnosed with epilepsy in childhood. Some people had multiple seizure types, although notably tonic-clonic seizures were common. On average, participants experienced 2–3 seizures a month and rated them as somewhat severe-moderate.

Five clinicians participated in interviews: four nurses and one doctor. The nurses were specialists in intellectual disability and/or epilepsy, and the doctor specialised in intellectual disability psychiatry. Four clinicians had delivered the interventions, and one had supported recruitment and observed some of the intervention sessions. One clinician who had delivered two intervention sessions had left the NHS Trust and was not able to be contacted about the interviews.

Three themes and seven subthemes were identified following reflexive thematic analysis (Figure 1). The three themes were ‘What epilepsy means for me’, ‘Preparation is key for meaningful book use’ and ‘Facilitating personalised epilepsy care in clinical consultations and the community’, and these will be discussed in turn.

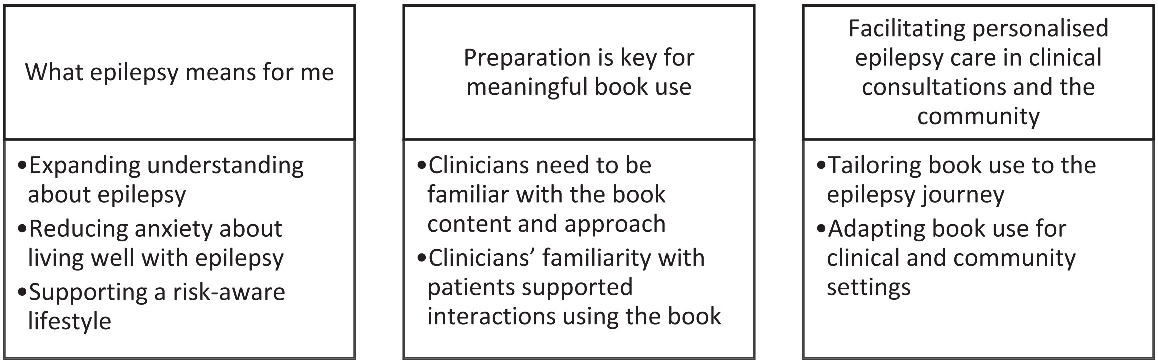

FIGURE 1 | Final themes and subthemes.

3.1 | Theme 1: What Epilepsy Means for Me

Patients enjoyed reading the book and most highlighted that having a picture-based narrative, rather than text-based, was helpful. Relating to the book was important, and using the book as a prompt to discuss the patients' experiences was key for all groups of participants. This was suggested to lead to benefits such as reduced anxiety, increased knowledge and greater confidence around epilepsy management.

3.1.1 | Subtheme 1.1 Expanding Understanding About Epilepsy

Participants commented on how the book reinforced and extended their understanding about epilepsy. Being able to relate the book to themselves was felt to be an important factor in helping patients engage with the book and support their understanding and learning about epilepsy.

> *I think it [the book] would increase their understanding, and they'd be able to relate, because relate, want to relate it to themselves. Rather than just giving a leaflet or just talking at them.*
>
> Clinician 03 talking about book use in routine practice

Some patients noted that they understood the book more after reading it multiple times at home, highlighting that use outside of a single clinical consultation is important.

> *she [the clinician] did say to me try and get used to the book, and try and read it a bit more, and that you would understand it. The more you read it, the more you understand it.*
>
> Patient 12

3.1.2 | Subtheme 1.2 Reducing Anxiety About Living Well With Epilepsy

The understanding promoted by the book appeared to help some patients to accept their epilepsy more and reduce anxiety about having seizures and/or everyday life with epilepsy. The book also highlighted that other people experienced epilepsy, which offered reassurance to some patients.

> *He's not more upset like before; he's more calm and accepting these things much easier than... Yes, you're better now.*
>
> Carer 08

3.1.3 | Subtheme 1.3. Supporting a Risk-Aware Lifestyle

The book was felt to support patients to understand that self-management was important to minimise their risks. Data from clinicians primarily contributed to this subtheme, and they felt that the book could be helpful in supporting with specific aspects of lifestyle adaptation, as needed.

> *So if they have a problem with compliance of medication or taking their medication, we might want to focus on that, or if they're going out and wanting to drink, we may want to focus on that part.*
>
> Clinician 01

There were limitations to this, as some participants noted that the book did not necessarily depict the key epilepsy management factors in patients' lives, for example, the use of rescue medication.

3.2 | Theme 2: Preparation Is Key for Meaningful Book Use

3.2.1 | Subtheme 2.1 Clinicians Need to be Familiar With the Book Content and Approach

All clinicians received a face-to-face training session from Beyond Words and/or the research team. Clinicians reflected on this training and shared that they found the role-play exercises and service-user input particularly helpful. This was particularly useful to highlight the style of prompting, which was intended to be open and support patients' interpretation of the story. This was noted to be quite different from the typical style of communication in clinical consultations.

> *it's quite different from what my role usually entails. So, actually, it was quite helpful to know how far to lead patients in...or participants in the questioning style. How open to keep the questions, and when to—at which point to maybe try and close in. Because in our consultations we often are giving lots of information, as doctors, and we tend to... It means a lot of our questions become quite closed, and often we do have to be quite explicit and just tell people what we think is going on.*
>
> Clinician 03

Familiarisation with the narrative enabled clinicians to support the reader with their interpretation. Although clinician's data primarily contributed to this subtheme, the importance of familiarisation was also reflected by patients and carers who noted that the clinicians were able to explain the book to them and help them read it. This was expressed by Patient 63, who noted that the clinician 'let me explain it, and, actually, she explained it to me as well, which is really understandable'. The use of the word 'let' potentially implies that this was not the norm for the patient's clinical interactions but the balance of being able to read the book herself with the support of the clinician appears to have been received well.

3.2.2 | Subtheme 2.2: Clinicians' Familiarity With Patients Supported Interactions Using the Book

Knowledge about the patients' epilepsy and their life helped clinicians to support patients to relate the book to their own experience. Understanding patients' anxieties and feelings around epilepsy helped the clinicians to use the book in a sensitive and helpful way.

> *I know from experience with that patient, she would not be able to read that book as if it was for herself; she would have to read it or interpret it as talking about someone else, or using the main character as someone else. So, yeah, that's why I think, from my memory, I asked her to name some of the guys within the book.*
>
> Clinician 02

The benefit of using the book with clinicians involved in their routine care was also highlighted by patients and their carers.

> *Patient 66 associates talking about his epilepsy with Clinician 05. And I think, again, that's really helpful because it means that he feels that she understands his epilepsy; and it just gives him another opportunity to actually talk about how he feels about it.*
>
> Carer 66

Where clinicians were not familiar with patients in the study, one reported reading through their notes beforehand, and another reported responding to the patient's interests and incorporating this into the book reading.

3.3 | Theme 3. Facilitating Personalised Epilepsy Care in Clinical Consultations and the Community

Participants spoke about how the epilepsy book supported personalised care. It was clear that *targeted* use of the book was felt to lead to maximum benefit. This included considerations of when the book might best be used during someone's epilepsy journey, characteristics of patients who might find it most helpful, and how the book might be used in different settings.

3.3.1 | Subtheme 3.1: Tailoring Book Use to the Epilepsy Journey

The book was thought to be comprehensive and across the 54 pages, there were many different things to talk about. Clinicians felt that it would often be necessary to consider what key messages they wanted to convey before using the book with a patient to maximise the book's use.

> *Yeah, to just have an idea before that, which are the kind of really key bits of the book, which we're trying to deliver a message to the patient. Yeah, I think that would have—that might have been useful, just to have a think about that before.*
>
> Clinician 03

Some participants thought that the book would be best suited for people who were newly diagnosed with epilepsy, as it could support their understanding of epilepsy and their discussions with their clinical team and support network.

> *I think if anyone, if you, you know, if you haven't had a fit before, and you have been diagnosed then I think it will help other people, because I've had epilepsy for a long time, and I am aware and I do know what to expect.*
>
> Patient 202

Some participants felt the book would be most useful to people who experienced seizures similar to the book, as it would be easier to identify with the pictures.

> *I think it would be more applicable for people who have drop seizures, because I think that could... The picture they can relate to in a way that maybe Patient 02 can't personalise.*
>
> Carer 02

Generally, the book was felt to benefit the understanding of the patients in the study, although some participants noted that the book may be particularly useful for people with more severe intellectual disabilities or with nonverbal communication due to the use of pictures.

> *if their verbal communication is very minimal, we can still show them pictures, we can still talk through it, because, actually, it's an aid rather than just us talking and it's something else to look at.*
>
> Clinician 01

> *Because people who are non-verbal, they can't explain what their fits are like or anything, but this booklet could explain things.*
>
> Patient 60

3.3.2 | Subtheme 3.2: Adapting Book Use for Clinical and Community Settings

The majority of participants felt that the book could act as a tool to support patients' understanding in a clinical consultation, and that this would be an important and feasible activity to do in routine care. Although it was acknowledged that using the book involved extra time, the clinicians expressed that this was achievable within their workload because of the potential benefits.

> *I think if it was well-planned, we could fit that in...and identify who we would use it on, then, yeah, you could make those appointments just that little bit longer.*
>
> Clinician 04

Although the face-to-face training session was valued, clinicians noted that this may not be feasible in routine practice, and that short videos and/or written guidance would be appropriate too.

> *I don't necessarily think that they would need to have a formal kind of training, and I think that would just create more barriers, which we wouldn't want to do. But I think having something quite clearly documented about helpful hints, things to do, things which are perhaps less helpful would... I think that would be necessary because otherwise I think people would be, would feel quite lost*

> *and not really know what the objective is, and how they should be delivering information.*
>
> Clinician 03

Patients who had used the book at home felt that this was easy to do and had been helpful. Using the book with other professional groups (i.e., outside of those involved in intervention delivery), support workers, friends and family was also felt to be important. Some patients with epilepsy had already done this and others were planning to. Reported or expected benefits from this included increasing other people's awareness of the patient's epilepsy and also people's awareness of epilepsy in general.

> *if I go to the doctors, that's one thing I would take with me.*
>
> Patient 01 referring to the book

4 | Discussion

This study explored the perspectives of people with intellectual disabilities, carers and clinicians about using a picture-based book to support with epilepsy management in routine care. Book use was felt to be a useful addition to routine care as it supported patients' understanding about epilepsy, which in turn could lead to reduced anxiety and increased confidence in management. To achieve this, clinicians needed to be familiar with the book and the participants' needs and preferences beforehand. Participants reflected on how the book could be used in a targeted way to support patients who may benefit most from its use.

People with intellectual disabilities experience health inequalities and often do not receive accessible health services and information (Ali et al. 2013; Mastebroek et al. 2014; Newman, Fisher, et al. 2023; Oosterveld-Vlug et al. 2020; Ward et al. 2010). Easy-read information is sometimes used with the aim of making health information more accessible, although there is limited evidence for widespread access to easy-read resources (Newman, Fisher, et al. 2023) and their benefits (Chinn and Homeyard 2017). Chinn (2017) highlighted that easy-read information often does not represent the range and nuance of emotions and experiences associated with health conditions, and resources such as picture-based narratives can provide a more balanced alterative. The limited research about self-management interventions for people with intellectual disabilities and epilepsy suggests that accessible information presented in an interactive and supportive format may be beneficial (Dannenberg et al. 2016). Using the 'Getting on with epilepsy' book, that is, a resource with a more realistic depiction of life with a health condition, in a clinical consultation may support patients in sharing information and making decisions about their life.

Person-centred communication can be lacking for people with intellectual disabilities in health consultations (Chapman et al. 2018), including in epilepsy. Thompson et al. (2013) found that some professionals do not adapt their communication for patients with intellectual disabilities, and somewhat unsurprisingly, professionals therefore find it challenging to elicit information from patients directly and rely on information from carers. Providing 'Getting on with epilepsy' as an accessible resource in a clinical consultation could support person-centred communication, thereby facilitating patients to express their experiences and concerns.

The participants in this study highlighted barriers to implementation in routine care, but these were not perceived to be insurmountable. Clinicians acknowledged that additional or longer appointment times may be needed; however, if the book was being used to support a consultation, this was not seen as particularly problematic. As Watkins et al. (2022) highlight, reasonable adjustments such as adapting appointment times and using accessible information are essential in epilepsy care for people with intellectual disabilities.

In routine care, it is likely that clinicians would choose to use the book for some patients at certain points in their care, rather than for all patients on their caseload. In particular, some participants felt that the book may be best for people who experience tonic-clonic seizures, like those depicted in the book. It is important to note that this is somewhat at odds with findings from the video analysis of the clinical consultations using the book (Mengoni et al. 2024), which suggested that people with all seizure types were able to engage with, relate to and benefit from book use. Participants also felt that the book may be best suited to people with more severe intellectual disability and/or who communicated primarily non-verbally. Our ethical approval only permitted inclusion of people with the capacity to consent, and therefore our group of patients had a mild-moderate intellectual disability and the majority communicated verbally. Implementation research exploring how and with whom the book is used in routine care would provide further insights to inform best-practice guidance.

Familiarisation of the book was seen to be crucial before clinicians using it. Although face-to-face training sessions took place in this study, it is likely that this would not be feasible in routine care. Instead, written guidance may be helpful, highlighting key points such as using an open prompting style, whilst also balancing this with the need of a clinician to impart clear and accurate health information. It may also be that a short training video would be helpful, as highlighted in other evaluations of resources for people with intellectual disabilities (Maguire et al. 2022).

5 | Implications

Following the WIELD 2 study, written and video guidance have been produced with the aim of supporting clinicians and patients who wish to use the book (University of Hertfordshire 2023), and research exploring the use of this in routine care would be valuable.

Table 2 is adapted from the WIELD 2 guidance, showing the different levels of engagement when reading the book. The findings from WIELD 2 suggest that all three levels should be used where possible to gain maximum benefit, and clinicians should be encouraged to use open prompts to support people with learning disabilities, particularly when relating the book to their own experiences. In most instances, we would recommend that the full story is read, but there may be circumstances in which it is appropriate to focus on a subset of pages, for example, when discussing diagnostic tests.

TABLE 2 | Supporting reader engagement when reading 'Getting on with epilepsy'.

Level of reader engagement	Details	Example reading	Example prompts (if needed)
Describing	Describing events in the pictures, at a surface-level	'I think he's having a seizure there'	'What's happening on this page?' 'I wonder what they are doing?'
Inferring	Inferring how characters might be feeling or why they are acting in certain ways	'He's feeling really down'	'How do you think he might be feeling?' 'How does his face look?'
Relating	Relating the book to their own lives.	'The next day after I have a seizure, I stay in bed'	'Has that happened to you?' 'When do you take your medicine?'

6 | Limitations

Given the scarcity of research in this area, this study provides a valuable addition to the knowledge base. However, a higher sample size may have led to increased transferability of the findings. In addition, we were not able to include people without capacity to consent who are more likely to have severe learning disabilities, which is associated with a greater prevalence and severity of epilepsy (Sun et al. 2022). Furthermore, the carers present at the interview were not necessarily present when the patient used the book with the clinician. There was a small number of clinicians involved in intervention delivery, thereby restricting the sample size for this group.

Reflexive thematic analysis is a widely used approach, although there are common pitfalls as highlighted by Braun and Clarke (2022). A particular limitation for the WIELD 2 study was that this approach does not lend itself to exploring conversational and linguistic practices. To overcome this limitation, we conducted conversation analysis on the intervention sessions, which is reported elsewhere (Mengoni et al. 2024). Multiple coders were involved in our thematic analysis for pragmatic reasons, but this did add complexity to the data analysis approach as the analysts had different levels of experience and backgrounds that could affect their interpretation of the data. To address this, the lead author met with all analysts to discuss their coding and positionality, and ensure coherence in the final thematic structure.

Patients were asked to use the book at home after the clinical consultation, and many reported doing so either by themselves or with family, friends or support workers. However, this was not the focus of the study, and minimal data was collected about this. In the interviews, participants reported that using the book with a patients' support network, including professionals from different disciplines would be beneficial, so this would be a valuable avenue for future research. There is a need for social care staff to receive training and education about epilepsy for people with intellectual disabilities (Newman, Rudra, et al. 2023). Through using the book, it may be that this provides personalised information about how a particular patient experiences epilepsy and highlights their support needs. Importantly, using the book in settings beyond clinical consultations would also support 'capable communities', whereby epilepsy awareness and training are extended beyond health settings to social and community settings that people with intellectual disabilities access (Shankar 2023).

7 | Conclusions

People with intellectual disabilities often do not have equitable access to health services and information provision, despite experiencing health inequalities. Epilepsy care should be accessible and tailored to the needs of a particular patient at a particular time, including for people with intellectual disabilities. The use of a picture-based book in a clinical consultation was felt to support this aim by patients, carers and clinicians, and its use should also be explored in home and social care settings.

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Conflicts of Interest

The authors declare that there are no known conflicts of interest. Please note that the publishers of the book were not involved in the design, conduct, analysis or write-up of this study.

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