Using a picture-based book to support epilepsy care in clinical consultations for people with intellectual disabilities

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ABSTRACT

Background and aims: People with intellectual disabilities are more likely to have epilepsy than the general population. A picture-based book, Getting on with Epilepsy, may help to improve their epilepsy management and quality of life. The present study aimed to explore how the book could be best used in routine clinical care.
Methods: Twenty people with epilepsy and intellectual disabilities were video-recorded using the Getting on with Epilepsy book with a nurse or doctor. This was analysed using conversation analytic methods. Eighteen patients and five clinicians took part in interviews to explore their views on book use, which were thematically analysed. All data were then synthesised to form themes.
Results: Three themes were identified which demonstrated the importance of (1) understanding the book depicted seizures (2) relating the book to the participants' experiences (3) using the book as an education and information tool. The themes highlighted the techniques and approaches that clinicians used to facilitate understanding. Some tensions and differences were noted between training and implementation in routine practice, particularly around prompts in themes 1 and 3 intended to correct or change participants' interpretation of the book.
Conclusions: The Getting on with Epilepsy book can be used in routine clinical practice to support people with intellectual disabilities and epilepsy. There was a balance between exploring patients' narratives and understanding with the need to convey clinical information, and this may also apply to the use of other accessible resources.

1. Introduction

Epilepsy affects approximately 22 % of people with intellectual disabilities [1], compared to 0.76 % of the general population [2]. People with intellectual disabilities are also more likely than people in the general population to continue having seizures despite taking multiple antiepileptic medications [3,4]. Many people with epilepsy and intellectual disabilities also experience physical and mental health comorbidities [5]. Epilepsy can have a significant impact on the lives of people with intellectual disabilities, for example reduced engagement in

work, decreased quality of life, more hospitalisations, higher health and social care costs and increased mortality [6–10].

People with intellectual disabilities can experience barriers to accessing appropriate healthcare services. This can be for many reasons including healthcare professionals' lack of specialist training and knowledge, difficulty in accessing timely support, not being listened to and incomprehensible healthcare information [11–13]. Therefore, it is important that people with intellectual disabilities receive appropriate and timely information about their condition(s) to facilitate shared decision-making, self-management and empowering interactions with

Table 1
Participant demographics.

	Mean (standard deviation) / Number of participants (%)
Age (years)	34.05 (15.82)
Gender	
Male	7 (35 %)
Female	13 (65 %)
Ethnicity	
White British	19 (95 %)
Black Caribbean	1 (5 %)
Home setting	
Supported accommodation / group home	10 (50 %)
Family home	8 (40 %)
Tenancy	2 (10 %)
Time since diagnosis (years) [a]	25.26 (21.38)
Type of seizures	
Tonic clonic	18 (90 %)
Focal	8 (40 %)
Absences	2 (10 %)
Number of seizures in last month [a]	2.68 (3.00)
Severity of seizures in last month [b]	2.50 (1.16)

[a] n = 19.
[b] n = 14.

healthcare professionals [13–15].

Easy-read health information is sometimes provided to people with intellectual disabilities as a reasonable adjustment to information provision. This often takes the form of leaflets with short sentences, accompanying pictures and accessible language. As Chinn and Homeyard [16] highlight, there is a need to go beyond information provision and to use such resources to provide personalised support that meets a particular individual's needs. The limited research regarding people with epilepsy and intellectual disabilities suggests that accessible information presented in an interactive and supportive format may be beneficial, for example via peer discussion, role play and nurse or carer support [17].

As a potential alternative or addition to easy-read information, the Getting on with Epilepsy book is a picture-based book telling the story of a young adult who progressively learns how to manage his epilepsy [18]. This capitalises on visual literacy to empower people to construct a meaningful understanding of epilepsy, which they are supported to apply to their own situation through discussion [19]. In a feasibility randomised controlled trial, the WIELD study [20] found that using the Getting on with Epilepsy book as an intervention had a potential benefit on epilepsy-related quality of life. Furthermore, people with intellectual disabilities, family members and support workers enjoyed using the book and felt that it may increase epilepsy knowledge, improve understanding of epilepsy management and prompt discussions about the experience of living with epilepsy. However, the intervention was delivered by a research nurse in a research session, and the intervention session was not observed. Therefore, it is difficult to know whether the findings apply to book use in routine clinical care and how the book can best be used in a routine clinical setting to promote potential benefits.

The present study aimed to explore how the Getting on with Epilepsy book was used in clinical consultations with people with intellectual disabilities and epilepsy. Specifically, it aimed to identify important components of book use in this context that may lead to improved epilepsy management and quality of life in routine care to inform and improve clinical practice.

2. Methods

2.1. Design

This was an intervention study with an observational and primarily qualitative design. All participants received the intervention (using the Getting on with Epilepsy book with clinicians) and this was video-recorded. Semi-structured interviews, including video elicitations, were also carried out with participants and clinicians.

Activity analysis was used to identify the structure and activities within each intervention session. This has been used in previous research of patient-clinician consultations to analyse patterns of interactions [21]. Conversation analysis was then employed to explore communication practices in the intervention sessions in detail. Conversation analysis has been used in healthcare settings [22,23], including with people with intellectual disabilities [24]. Reflexive thematic analysis [25] was used to analyse interviews with clinician and patients, and data were synthesised into themes.

2.2. Participants and recruitment

Our aim was to recruit 20 people with intellectual disabilities. Participants had to be over 18 years old, be likely to engage with the book for 15 minutes and have capacity to consent to the study. They had to have experienced at least one epileptic seizure in the past year and be currently attending epilepsy services. They were excluded if they had a diagnosis of dementia or if they had used the book within the past year.

Clinicians were recruited if they worked with people with intellectual disabilities and epilepsy and were willing to attend training and deliver intervention sessions.

Our target sample size of 20 was based on likely recruitment rates from the WIELD study [20] and the concept of information power [26], which is that the more relevant information a sample holds, the fewer participants are needed. Participants were recruited from two NHS Trusts in the East of England (Hertfordshire Partnership University NHS Foundation Trust (HPFT) and Norfolk Community Health and Care (NCH&C)) during a 9-month period from May 2019 to Feb 2020.

Clinicians and research and development teams within the NHS Trusts screened caseloads and shared information packs with potentially eligible patients. All study documents intended for patients were designed in easy-read format, with input from an expert by experience group. The patients and/or carers returned a form to indicate that they were happy for their contact details to be passed to the university-based research team. The research team then contacted the patient/carer to discuss the study with them over the phone, and to arrange a home visit. At this visit, capacity to consent was assessed by the researcher. If the patient wished to take part and was deemed to have capacity, then consent was taken.

2.3. Clinician delivery of intervention

The Getting on with Epilepsy book consists of 54 pages each showing an illustrated picture which together depict the story of a man who experiences seizures, which appear to be tonic-clonic, and who then undergoes investigation and treatment. At the end of the book, there is a suggested written storyline and some further information about epilepsy.

Clinicians were provided with face-to-face training about how to use the book from the Books Beyond Words team and/or a member of the research team previously trained by Books Beyond Words. Training included an outline of the research project, an overview of Books Beyond Words, demonstration of using the book and role play exercises. Key principles for using the book included the reader being the story-teller and holding the book, and the facilitator using a layered reading approach, which involves primarily using open questions to support the reader's interpretation rather than closed or leading questions. The

research team also produced an intervention guidance document based on the training and study design, which was shared with the clinicians.

Following consent, the researcher informed the relevant clinician that the participant had agreed to take part and the clinician scheduled the intervention session as they wished. This was recorded using a video camera and an audio recorder. The research team were not present at this session. A maximum length of 30 minutes for book reading was suggested, but clinicians were encouraged to use their judgement for each participant. The participant was asked to use the book at least two more times at home over the following four weeks, and the participant then kept the book. The clinician completed an intervention log after the session recording key information such as length of session, if all the book was read, if carers were present and if so, if/how did they contribute.

2.4. Data collection

2.4.1. Demographics questionnaire

Participants answered questions about their demographics and epilepsy prior to the intervention including age, gender, ethnicity, when epilepsy was diagnosed, seizure type, frequency and severity, and medication use.

2.4.2. Intervention recordings

The video recordings of the intervention were the primary source of data for this study. Recordings were transcribed using Jeffersonian conventions (Supplementary File 1) to facilitate a conversation analysis approach. Non-verbal communication such as nodding or shaking their head and direction of eye gaze was also included.

2.4.3. Participant interview

Participant interviews took place approximately four weeks after the intervention session. Interviews were audio-recorded.

Video elicitation is a technique used to facilitate participants' reflections on their thoughts and feelings during an activity or event [27]. As part of the interview, participants took part in video elicitation to add insight into their understanding and interpretation of the book. The researcher used a laptop to show short video clips of up to five key points from the intervention session to the participant and prompts were prepared to facilitate the discussion about the video clips. The clips were chosen in line with the aims of the book and research questions, for example when the participant described the character as having epilepsy, instances of the participant relating the book to their own experiences, and/or any misunderstandings of the book. Prompts were adapted to each clip shown and included questions such as 'can you remember what you thought about this picture', 'what did you think of the question that the nurse/doctor asked you?'.

Following the video elicitation, the researcher conducted a semi-structured interview with the participant to explore their views about using the book, with a focus on if/what they found beneficial for their understanding, management and experience of epilepsy. A schedule was

Table 2
Overview of clinicians who were involved in the intervention.

Clinician	Number of intervention sessions	Took part in semi-structured interview?	Took part in video elicitation?	Interview format
WC01	5 [a]	Yes	No	In person
WC02	5	Yes	Yes	In person
WC03	1	Yes	Yes	Video call
WC04	3	Yes	No	Phone call
WC05	9	Yes	Yes	Video call
WC06	2	No	No	n/a

[a] observed 5 sessions but did not deliver any.

used to guide discussion with open-ended questions such as 'What did you think about using the Getting on with Epilepsy picture book with the nurse/doctor?' which were followed up with prompts as appropriate, for example 'what did you like/not like about using the book with the nurse/doctor?'. If a family member or support worker was present, they and the participant were asked if they would like to take part in the interview and, if so, written consent was provided.

2.4.4. Clinician interview

The interview with clinicians took place after the clinician had conducted all their intervention sessions. Interviews were audio-recorded and followed a similar format to the interview with the participants with intellectual disabilities with video elicitation and semi-structured interview components. Video elicitation aimed to provide an understanding of clinicians' thoughts and actions during the intervention sessions they conducted. The procedure followed the same format as for the participants, but also included prompts about their perceptions of the participants' thoughts and feelings and clips were drawn from across the different participants that a particular clinician worked with. Example prompts included 'what factors influenced you to focus on this picture?' and 'what did you think the participant understood about that picture?'.

The semi-structured interview aimed to understand experiences of using the book with participants, how the intervention fitted in the service context, and to explore facilitators and barriers to delivering the intervention in routine care. Broad questions were asked, including 'what did you think about using the book with participants?' with follow-up prompts such as 'what did you find easy/difficult about using the book and why?'.

2.5. Data analysis

2.5.1. Intervention recordings

The transcriptions of the intervention recordings were transferred to Microsoft Excel. There were three analysts (SM, CHW, TKC) and each analyst began by reading the transcripts, watching the video, and adding in book page numbers and non-verbal communication such as nodding or shaking their head and direction of eye gaze to the Excel analysis table.

Drawing on previous research of patient-clinician interaction [21,28,29], the first step of analysis was to code intervention activities. The activity analysis coding structure (Supplementary File 2) was drawn from the intervention guidance and training, and example codes were 'Participant describing picture – surface-level e.g. what is happening' and 'Clinician prompting to think about own experiences'. This was followed by additional analysis on interactional sequences relating to the research questions, in particular using conversation analysis to understand if/how clinicians and participants mutually constructed a shared understanding of the book, drawing on conversational features including silences, pitch and elongation.

Analysis was first undertaken on five transcripts, including one transcript which was double-coded. The analysis team then met to identify phenomena of interest [30], which were formed into themes. The remaining 15 transcripts were analysed by coding intervention activities and nonverbal communication as previously, followed by a focus on the interactional sequences relating to the identified themes.

The themes aimed to reveal common features of intervention delivery across participants. Attention was also paid to examples of 'telling cases' [21]. Telling cases included instances where activities appeared to be unexpected by either the participant or clinician and how this was responded to, for example where participants provided an unexpected response to a clinician's prompt. Such interactional issues provide insight into factors affecting book use and how this may impact on wider implementation. The results section incorporates both representative and telling cases to illustrate themes.

2.5.2. Interviews and video elicitations

The video elicitations and interviews with participants and clinicians were transcribed and thematically analysed following Braun and Clarke's six-phase process [25]: familiarization with the dataset; coding; generating initial themes; developing and reviewing themes; refining, defining and naming themes; writing up. Three analysts (CHW and two postgraduate research assistants) coded independently on NVivo, and also had regular conversations with a further member of the research team (SM) to reflect on the coding and discuss the thematic structure. The initial coding was both descriptive (for example, information about participant's epilepsy status) and latent (for example, what may affect implementation in routine practice). Two of the 23 transcripts were double-coded (9 %).

2.5.3. Data synthesis

Following initial analysis, data was synthesised by theme primarily drawing on the analysis of the video-recorded intervention sessions and also incorporating contextual data (for example, person's type of seizures, duration of epilepsy) and the interview data. Each theme was primarily analysed by one analyst but the team met frequently to discuss and synthesise findings.

The interview data (both video elicitation and semi-structured components) contributed to the analysis in two ways: on an individual participant basis and an overall level. The interviews for each participant, particularly the video elicitation element, were considered alongside the conversation analysis of their intervention session to contribute to our interpretation of particular interactional sequences. The thematic analysis of the interviews (to be reported in full elsewhere) were incorporated into the overall understanding of each theme. This approach to data synthesis is reflected in the results section where an overview of the theme is presented and exemplified by particular cases from the intervention session with additional insight from the interviews as appropriate.

2.6. Ethics

All procedures were performed in compliance with relevant laws and institutional guidelines. Ethical approval for the study was granted by the South Central Oxford C NHS Research Ethics Committee (IRAS: 254590; REC reference number: 19/SC/0029), and governance approval was granted by the Health Research Authority, the NHS Trusts involved and the University of Hertfordshire. Informed consent was obtained and as part of the ethical approval process, the Research Ethics Committee stipulated that only people with capacity to consent could take part in the research.

3. Results

3.1. Participants

Twenty-two people consented, but two withdrew prior to the intervention session and are not included in the analysis. One withdrew due to loss of capacity as reported by their carer and one withdrew as they no longer wanted to be video-recorded and this was a requirement of participation. Twenty people with intellectual disabilities and epilepsy took part in the intervention (see Table 1 for demographics), and of these 18 people took part in the post-intervention interview; one was unable to be contacted and one declined to take part in the interview. Due to Covid-19 restrictions, three of the interviews took place over the phone and therefore the video elicitation did not take place.

Participants ranged in age from 18 – 67 years old, with the average

age being 34.05 years old. The sample was predominantly White British and most people lived with support, either in the family home or in supported/group accommodation.

The length of time since epilepsy diagnosis ranged from 2 years to 65 years, with a mean of 25.26 years. Seizure types were varied and multiple, although the majority of people reported experiencing tonic clonic seizures. All participants reported taking medication for the seizures. The frequency and severity of seizures were highly variable (ranked 1–4, with 1 = very severe and 4 = mild), with some people unable to answer questions about their seizures due to the unpredictability and varying nature.

Clinicians who delivered the intervention were also invited to take part in interviews. Five clinicians delivered the intervention sessions across the two NHS Trusts: three nurses and two doctors specialising in psychiatry. One clinician who had delivered two intervention sessions had left the NHS Trust and was not able to be contacted about the interviews. The other clinicians all consented to take part in the interviews, along with an additional clinician who had supported recruitment and was present during intervention delivery (Table 2). Two interviews took place in person, and due to Covid-19 restrictions, three interviews took place remotely. Two clinicians did not take part in video elicitation: one because the interview took place over the phone and one because they were involved in recruitment and attended the intervention sessions, but did not deliver these.

3.2. Intervention sessions

Fifteen intervention sessions took place at the participant's home (all in HPFT) and five took place at a community hospital (all in NCH&C). The average length of time that it took to read the book was 27.48 minutes, ranging from 15 to 50 minutes. Fifteen participants attended the intervention session with a carer. Twelve carers contributed to the session, and their involvement consisted of helping the clinician set up, reassuring the participant and providing minimal prompts to the participant. Thirteen carers contributed to the post-intervention interview, and the level of their input to the conversation varied.

3.3. Themes

Themes were identified as:

1. The importance of understanding the book is about epilepsy
2. Prompting to support participants relating the book to their own experiences
3. The clinical value of using the book to inform and educate

3.3.1. The importance of understanding the book is about epilepsy

The majority of participants described the events in the book as relating to epilepsy, most commonly describing the character having seizures on pages that depicted this. Over half of the participants talked about the book depicting epilepsy independently. Where people required prompting, clinicians often provided generic prompts such as "what has happened to the man?" or prompts to relate the book to their experiences such as "have you ever fallen down like that?", which often led to the participant labelling the picture as depicting epilepsy.

In the interviews, the clinicians expressed a clear view that it was important that the participant understood the book was about epilepsy, for example:

"I do just wonder whether everybody would know that was a fit, and then what they would take away from the book if they couldn't grasp that, because that's quite fundamental, I think, to the book that you understand that particular picture. And then I wondered what would happen then, whether... How helpful the book is if you don't get that key point?" Clinicians WC03 reflecting on the first image of a seizure

Therefore, some clinicians would provide the description of a seizure if the participant did not do so. As shown in Extract 1, clinician WC02 did this on a page depicting a seizure early in the book for participant W204 who then went on to independently describe pictures as relating to epilepsy in later pages of the book. This suggests that the clinician's input supported W204′s understanding of the book.

Extract 1: W204

116	Clinician	So it looks to me like Greg has maybe fa=fallen
117		over,
118		(2.5)
119		Because he's laid on the floor.
120		(0.8)
121	Participant	Yeah.
122		(0.8)
123	Clinician	And do you think he might be having a seiz↑ure?
124		(1.8)
125	Participant	I don't kn:ow.

There were four individuals for whom it was unclear if they understood the book was about epilepsy. There was no clear pattern about why this might be the case, as different clinicians delivered the sessions, and the participants had different seizure types with varying frequency. For one of these participants, the clinician labelled a picture as depicting epilepsy to which the participant agreed, but in contrast to W204, the participant did not then discuss any other pictures in relation to epilepsy. For the other three participants, the clinicians did not describe any pictures as relating to epilepsy. Extract 2 shows one of these cases, and a lack of prompting from the clinician can be seen despite opportunities to do so (for example at line 131). In their interview, clinician WC04 stated that they felt that in general, the participants "should be leading the session, and they should be interpreting the book their way" and they also reflected that for this particular participant, "I didn't want to raise their anxieties, I was allowing them to read the book as best they could".

Extract 2: W46

126	Participant	Because it did happen to me when I was at school ()
127		like that [()]
128	Clinician	[Did it?]
129	Participant	It happened to me when I was about 18 to 19 and 17
130		there and I was like (at school) yeah.
131	Clinician	↑Ok↓ay.
132		(0.4)
133	Participant	Yeah it happened at=at school before to <u>me</u>.

One case in particular exemplified how the clinician's knowledge of the participant enabled them to draw on the training and use their clinical judgement to best support the participant during the reading. On the first depiction of a seizure, participant W08 described the character as being "shaky and angry" and suggested that this was because of a gunshot. The use of the word "probably" (Extract 3, line 97) indicates that he may not be sure about this interpretation, and the clinician used the phrase "you think" to query this. The conversation continued with the clinician using different prompts, such as asking for alternative interpretations and asking how the character might be feeling, but the participant did not describe the picture as depicting a seizure. However, on a later sequence of pages, W08 described the character as having

experienced a seizure with no prompting.

Extract 3: W08

93	Participant	And then he's got a lot of blood (0.5) [on his head.]
94	Clinician	[Oh]
95		how do you think that happened?
96		(1.4)
97	Participant	<u>Probably</u> from the gun (.) somebody shot him with a
98		<u>gun.</u>
99	Clinician	>You think somebody ↑shot him with a gun<?
100	Participant	I think so yeah.
101	Clinician	You think that's why he was on the floor?
102	Participant	Probably yeah.

In their video elicitation, clinician WC05 explained that "his [W08's] epilepsy is a difficult thing for him to accept, and we have to be careful how we talk about it" so they chose to prompt but not label the image as showing a seizure. In their semi-structured interview, they also reflected that W08 had opened up more about epilepsy after the intervention:

"after we'd done the intervention, we were traveling to a clinic appointment at [hospital name], and I was talking to mum, you know, how are you getting on and did you manage to do the book, blah-blah-blah. And he actually joined in and talked about his 'elilepsy' for the very first time, and I thought a-ha!" WC05

W08 reported that he liked the book in his semi-structured interview and had continued to use it at home, and his parent who was at the intervention session echoed WC05′s reflections about the benefits.

"He's not more upset like before. He's more calm and accepting these things much easier than... Yes, you're better now." W08 parent

3.3.2. Prompting to support participants relating the book to their own experiences

The majority of participants related the book to their own experiences, although in contrast to understanding the book was about epilepsy, most participants required prompting rather than doing this independently. Typically, the clinician prompted about the character's feelings and built on the participant's response, which often led to the participant talking about their feelings and experiences of seizures.

For some participants, this approach seemed to establish that talking about their experiences was part of the book reading conversation and they then started to volunteer more information, offering an insight into their experiences of epilepsy, its management and their goals. Prior to Extract 4 below, clinician WC05 asked if participant W63 had experienced injuries during seizures like the book character and she talked about banging her head. She then talked about her epilepsy alarm and why this was not helping her. This offered the clinician insight into epilepsy management and the clinician reassured the participant that they would discuss this in more detail.

Extract 4: W63

112	Participant	That's why I've got an epilepsy alarm up in my bed.
113	Clinician	Oh you have one yeah.
114	Participant	But that doesn't work (0.7) because mainly I'm off
115		the bed because I wander.
116	Clinician	When it happens you're off the bed yeah.
117	Participant	Yeah because I wander.
118		(0.7)
119	Clinician	You wander. (0.4) okay we can talk about what we can
120		do about that afterwards y↑eah okay.

Three participants primarily described the pictures at a surface-level, for example what the character was doing. They did not talk about their own experiences or feelings in relation to the book much or at all.

Typically, these participants did not respond to prompts or indicated that they were unsure and the clinician would move on to the next page. Extract 5 shows how WC05 first used a generic open prompt, followed by a prompt about the character's feelings using the image as a support, and then asked about the participant's experience but without much success. It is worth noting that W10, and the other participants who did not talk about their own experiences much, reported that they had experienced one seizure in the last month which is below the mean for the participants in this study.

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Extract 5: W10

166  Clinician    What do you think=what do you think is happening
167               there?
168  Participant  (h)
169               (2.1)
170  Clinician    Just=just what do you think=what would you say
171               about his (h) face=what do you think?
172               (1.2)
173  Participant  He's sad.
174  Clinician    He's sad?
175  Participant  Mm.
176  Clinician    Do you feel like that when you=when you're not
177               feeling well?
178               (2.1)
179               How do you feel when you're not feeling well?
180               (3.7) ((participant looks at family member))
181               Would you say that it's something that you would
182               feel when you're not feeling well=feel the same way
183               or_No?
184               (1.1.) ((participant shakes head))
185               No? Okay that's fine=that's all right
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In their interviews, clinicians highlighted that exploring participants' experiences of epilepsy was an integral part of why the book would be helpful in clinical practice. For some clinicians, they did not know the participants well so it was useful for them to use the book as a basis to explore this.

> *"And I think it 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, I think that's probably its main strength."* WC03

> *"I was trying to ascertain how she feels after her seizures, so if she feels sad, if she feels tired, ill, confused"* – WC02 regarding a participant that they did not know prior to the intervention session

Being able to relate to the book was important to participants too, with participants reflecting in their interviews about how they incorporated their own experiences into the book reading and that this helped them enjoy the book.

> *"I've just really enjoyed it, and I just feel that it understands how you feel."* W12

3.3.3. The clinical value of using the book to inform and educate

There were several key pages that were used across the intervention sessions to share information, including images depicting medication, diagnostic tests and lifestyle considerations such as drinking alcohol and swimming. Many participants required prompting to consider these images from an epilepsy management perspective. The clinicians tended to use open prompts initially, for example "What is happening here?" to prompt the participant to think about the image in more detail. They also referred to the picture itself to scaffold participants' description and understanding, for example asking what they could see on the page.

Compared to the other themes, the clinicians more often provided specific and focused prompts to guide the conversation. An example of this can be seen in Extract 6, where clinician WC05 asked participant

W60 for their views on the characters' actions in relation to their epilepsy. Later in the conversation, W60 volunteered that "if I have a glass of wine that's it. That's my limit and no more", providing information about her approach to epilepsy management.

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Extract 6: W60

189  Clinician    So what's happening there=where is he?
190  Participant  He's out having a drink?
191  Clinician    M::m what do you think about that (0.4) with his
192               epilepsy?
193  Participant  Not=not good.
194  Clinician    Not good is ↑it?
195  Participant  Because well with some medication you  [can't]
196  Clinician                                          [You]
197               shouldn't mix.
198  Participant  You=you=you can't drink alcohol.
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Clinicians were more likely to offer their own interpretation or correct participants' description on epilepsy management pages than other pages. This was largely done in a conversational style and these new interpretations tended to be accepted by participants and incorporated into their understanding. In Extract 7, participant W01 was looking at a page which depicts a cross next to a large glass of beer and a tick next to a small glass of beer. Clinician WC04 offered an alternative interpretation of the picture on line 654, shown with an elongated vowel (b::ig) to highlight that the image is specifically about not having a large drink of alcohol. WC04 reflected in their interview that "having the picture of the big and the small beer is helpful, so you can… It's a visual aid".

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Extract 7: W01

651  Clinician    This is telling him, (0.2) don't have?
652  Participant  Ah yeah don't have anything to drink.
653               (0.4)
654  Clinician    Don't have a b::ig drink.
655  Participant  A big drink.
656  Clinician    Whereas maybe a half is okay?
657  Participant  Yes.
658  Clinician    Do you think?
659  Participant  Yeah.
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Two participants did not talk about epilepsy management. WC04 carried out both sessions and they did not prompt either participant about this. In their interview, they reflected that both of these participants were anxious about their epilepsy and so they were focused on letting them lead the session and read the book how they wanted to.

Using the book to inform and educate had clear value for clinicians and participants, with potential benefits after the intervention session. From the clinicians' perspective, the book was particularly useful to check and discuss participants' understanding of epilepsy management, and this was a focus of the book reading for them.

> *"But I feel it's my way of saying life can still go on, and people can still enjoy activities, but just to remember there are risks and keep safe. So it's just that you can have a normal life, I think that's what I was trying to get at."* WC05

Some participants spoke about epilepsy management in their interview, including how they liked those pages of the book or how they thought differently about epilepsy management now.

> *"Oh, I liked the bit about how it's understandable, like you can't drink alcohol because it could trigger it. You can't – you have to take your medicines at a certain time, and all that."* W63

> Interviewer: *"Have you done anything differently? Has it [using the book] made you change anything that you do?"*
> W11: *"Yeah, because I would have just gone in the kitchen anyway and do things, but now I don't. If I feel…unwell and I don't do it."*

4. Discussion

This study aimed to explore how the Getting on with Epilepsy book could best be used in a routine clinical setting to support quality of life and epilepsy management for people with intellectual disabilities and epilepsy. Clinicians and participants used the book together, and the majority of participants spoke about the book depicting epilepsy, without prompts or with very open and generic prompts. Many people were able to relate the book to their own lives when prompted. This component of book use was seen as important as it helped participants to engage with the book and open up discussions about their experiences and feelings. Clinicians felt that understanding the epilepsy management element of the book was important, and participants also found this beneficial. Clinicians often took a more instructive approach to these pages, using more direct or corrective prompts, so they could share accurate and clinically relevant information.

Participants who experienced a range of different seizure types and frequency were able to recognise that the character was having a seizure. However, participants who did not relate the book to their experience much or at all had fewer than average seizures. Therefore, it may be that epilepsy did not impact on their lives as much as for other participants. Participants in this study had different styles of communication, although most communicated predominantly verbally, and there did not seem to be a relationship with how they engaged with the book. This may be because the emphasis of the book, and the training, was on the readers' interpretation and story-telling communicated in their own way [19].

In line with training, open general prompts were predominantly used by clinicians to support story-telling, and this was often successful in supporting the participant to discuss the character's actions and participant's experiences. Similarly, in social care settings with adults with intellectual disabilities, open-ended questions followed up with hints and elaborations, as opposed to forced-choice questions and alternatives, have been found to enable people to best reflect on their experiences [31]. Where deviations from this approach occurred in the present study, this was typically in two scenarios: firstly, where participants did not label the book as depicting epilepsy and secondly on pages depicting epilepsy management. In these scenarios, clinicians were more likely to question the participant's responses by repeating their question, presenting options and/or providing their own interpretation. These practices could be seen as less supportive [32] but it was clear from the semi-structured interviews and video elicitations that clinicians felt that they needed to convey specific information relevant to clinical care. This suggests that they viewed these interactions as potentially 'teachable moments' [33]. This has some similarities with the findings of Antaki and Chinn [34], who explored how companions of people with intellectual disabilities intervened in medical consultations and found that there was a balance between prioritising the person's autonomy against the need to convey the necessary medical information. This sometimes resulted in companions providing very direct input, for example correcting people with intellectual disabilities about medical information.

In a typical consultation, clinicians often have information and lifestyle advice that they intend to share [35], and in this study the epilepsy management pages were used in this way to explain recommendations about lifestyle. Similarly, Chinn [24] found that doctors sometimes used easy read health information to support their recommendations about health behaviours rather than providing direct instructions, emphasising that the patient is the ultimate decision maker. However, in Chinn's study, the recommendations and resources were sometimes met with resistance, which was not the case in the present study. Chinn explored interactions in annual health checks where people may not have presented the clinician with a problem. In the present study, all participants knew that they were taking part in an intervention that may support their epilepsy. This suggests that framing interactions as supportive rather than monitoring may provide a positive context for clinical advice.

There were variations between how the clinicians operationalised and applied the training, particularly where they made judgements about whether to present new information and/or correct participants' interpretations. This may be minimised by clearer training and guidance about if and how this should be done. Guidance should emphasise that whilst open prompts should be the primary approach, clinicians can provide more direct prompts and/or new interpretations to highlight that the book is about epilepsy and to convey clinically accurate information about epilepsy management. However, it is important to note that there were several examples where clinicians used their professional judgement to make an active clinical decision not to prompt or provide 'correct' interpretations, for example for participants who experienced anxiety relating to their epilepsy. In the case of W08, this approach led to him independently talking about epilepsy but this was not the case for other participants. It may be that the book opened up discussion in a safe way for this participant, as the conversation was focused on someone else's seizures rather than his own. This demonstrates the importance of healthcare resources, such as Getting on with Epilepsy, being used in a context where the clinician is able to adapt their approach so it is useful and appropriate for that particular patient.

5. Limitations

People with moderate-profound intellectual disabilities are more likely to experience epilepsy than people with mild intellectual disabilities, and their seizures tend to be more frequent [5]. In the present study, only people who had capacity to consent could take part in the study, as stipulated by the ethics committee. People with more profound intellectual disabilities are less likely to have capacity to consent, and as such the group of people who took part in this research are not representative of the population of people with intellectual disabilities and epilepsy. Getting on with Epilepsy is designed for people with varying levels of intellectual disabilities and communication styles, therefore exploring the use of the book with a wider range of people would be valuable to inform clinical practice.

Previous research using the Getting on with Epilepsy book with people with intellectual disabilities [20] has suggested that it may be best suited for people who have been recently diagnosed. Reflecting the wider population of people with epilepsy and intellectual disabilities [36], the majority of people in this study were diagnosed in childhood. Therefore we are unable to explore whether the book may be most useful for people with recent diagnoses. However, many people with intellectual disabilities continue to experience seizures despite taking antiepileptic medication [3,4]. The present study suggests that using the book to open up discussions about epilepsy experience and management may be useful to people who continue to experience seizures regardless of when they were diagnosed.

One of the aims of this study was to explore book use in a routine clinical setting unlike previous research [20], but this was still in the context of a research setting with in-person training and an intervention handbook. This is likely to have provided more structure and guidance than in a real-life clinical setting. In particular, being video-recorded may have led to clinicians behaving differently and perhaps adhering more to the training than they otherwise would. The next step may be to provide less intensive training, perhaps in the form of online training, written guidance or videos [37]. The data from this study has been used to produce evidence-based video and written guidance about using the book in a clinical context, aimed at clinicians and people with intellectual disabilities [38]. This guidance means that people can access training and resources in their own time, and then use the book as they see fit in their practice. The next step would be to conduct research exploring the implementation of this guidance, for example with ethnography, interviews and/or a randomised controlled trial.

The focus of this study was book use within a clinical context. Although participants were asked to continue to use the book at home, this was not video-recorded or observed. The book may be used

differently by family members, support workers and when people with epilepsy use the book by themselves. In a home-use context, we hypothesise that the emphasis may not be as strongly on epilepsy management, differing from the book being used in a clinical context, but further research would need to explore this. On a related note, there was a small number of clinicians involved in this study and all were drawn from two regions in the East of England, limiting the transferability of our findings. Furthermore, they all had specific intellectual disability expertise and it may be that the book would be used differently by clinicians from different professional groups such as neurologists.

6. Conclusions

The evidence from this study suggests that the Getting on with Epilepsy picture-based book can be used in clinical settings, and was perceived as beneficial by both clinicians and participants. Analysis of the interactions during book reading highlight that the book may be used by clinicians in a slightly different way than the approach typically recommended by Books Beyond Words and adopted in the training for this study. However, the general approach of supporting and prioritising patients' interpretation was key and open prompts should be used as the starting point, with more corrective and direct prompts and interpretations being provided by the clinician as clinically relevant and appropriate. This approach is taken in our freely available video and written guidance based on the present study [38] and may also apply to other healthcare books in the Books Beyond Words series and other accessible information intended for people with intellectual disabilities.

7. Data statement

Data is not freely available as it is confidential, as per the participant information sheet and consent form.

CRediT authorship contribution statement

Silvana E. Mengoni: Writing – original draft, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Charlotte Hamlyn Williams:** Writing – review & editing, Project administration, Investigation, Formal analysis, Data curation. **Thando Katangwe-Chigamba:** Writing – review & editing, Formal analysis, Data curation. **Jamie Murdoch:** Writing – review & editing, Methodology. **Indermeet Sawhney:** Writing – review & editing, Resources. **David Wellsted:** Writing – review & editing, Supervision. **John Willmott:** Writing – review & editing, Project administration. **Georgina Parkes:** Writing – review & editing, Resources, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2024.109984.

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