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## Understanding patient experiences of using booklet-based vestibular rehabilitation with or without remote support for self-managing chronic dizziness.

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Manuscripts

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

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6 vestibular rehabilitation with or without remote support for self-managing chronic  
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Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

## ABSTRACT:

**Objective:** This study evaluates participants' experience of self-management of dizziness using booklet-based vestibular rehabilitation (VR) with or without expert telephone support. **Design:** Semi-structured qualitative interviews were conducted. **Setting:** Participants were recruited from primary care practices as part of a large RCT. **Participants:** Interviews were carried out with 33 people self-managing chronic dizziness using booklet based vestibular rehabilitation with or without expert telephone support. **Results:** Data were analysed using inductive thematic analysis. The majority of participants in both groups reported a positive experience of VR therapy, with many participants reporting an improvement in dizziness symptoms since undertaking the therapy. Participants in the telephone support group felt that a genuine relationship developed between them and their therapist within three short sessions, and described their therapy sessions as reassuring, encouraging and motivational. **Conclusions:** The VR treatment booklet appears to be a valued tool for self-managing chronic dizziness and people appreciate receiving remote telephone support.

### Strengths and limitations of this study

- Thematic analysis is a rigorous systematic approach to qualitative analysis.
- Recruitment continued until the data reached saturated.
- This study was nested within a RCT and explores patient experiences of the therapy.
- The sample inevitably comprises only of those people willing to be interviewed, and it is therefore possible that those who appreciated the therapy may be over-represented.

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## 6 INTRODUCTION 7

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10 Chronic dizziness is a common symptom, and is believed to affect up to 25% of the  
11 community [1]. Suffering from chronic dizziness can be debilitating and lead to loss  
12 of independence, reduced fitness, falls and fear of falling [2]. Dizziness is more  
13 common in older people, but it is estimated that one in ten working age adults suffer  
14 some degree of disability due to dizziness [3]. Significant disability, medication use  
15 and medical consultations due to dizziness have been found in more than 20% of  
16 people over the age of 60 [4], with 24% of dizziness being attributed to vestibular  
17 disorder [5].  
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31 The vast majority of people suffering from dizziness consult their General Practitioner  
32 (GP) in the first instance [5]. Dizziness is commonly encountered in primary care. It is  
33 estimated that 2% of all primary care consultations are for dizziness [4, 6], with this  
34 figure increasing to as high as 30% in people over 65 [7]. The majority of patients  
35 with dizziness seen in primary care have peripheral vestibular disorder, and serious  
36 sinister pathology in patients with no other symptoms is very rare [8, 9, 10].  
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Primary care patients with dizziness are typically treated and managed with  
reassurance and medication to relieve their symptoms [11, 12]. Reviews of the  
management of chronic dizziness have, however, concluded that no medication has  
well established efficacy in the treatment of dizziness, nor is any suitable for long-  
term use [9, 13]. Furthermore, many patients with chronic dizziness have needs that  
are not being met by healthcare [14]. Vestibular Rehabilitation (VR) is now the

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3 recommended treatment for dizziness [13, 15]. The central component of VR is a  
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5 programme of graded exercises consisting of eye, head and body movements designed  
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7 to stimulate the vestibular system and promote neurological adaptation [12]. VR  
8  
9 exercises typically induce dizziness symptoms to start with, but repetition for several  
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11 weeks typically results in partial or complete resolution of symptoms [16, 17].  
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13 However, very few patients with chronic dizziness currently have access to VR  
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15 therapy, as referral to specialist clinics where VR is typically delivered can be lengthy  
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17 and expensive [18, 19].  
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23 Yardley and colleagues [20] developed a booklet teaching home-based VR exercises  
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25 for the self-management of dizziness. The booklet was designed to promote adherence  
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27 to VR and address cognitive and behavioural factors that may contribute to the high  
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29 rates of psychological problems known to commonly accompany vestibular  
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31 dysfunction [21]. VR elements of the treatment booklet is discussed in the main trial  
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33 paper [22]. This booklet has been evaluated in several clinical trials, and has been  
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35 found to be a safe, effective, and cost-effective treatment for dizziness [20, 22, 23].  
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### 41 **Study context**

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45 This study was nested within a recent VR trial of booklet-based self-management of  
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47 dizziness in primary care [22]. VR trial participants were randomised to either a  
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49 routine care group, booklet only group or booklet with telephone support group. The  
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51 trial used the self-treatment VR booklet [20] to evaluate the cost-effectiveness of two  
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53 models of VR delivery for people with dizziness: booklet only and booklet with  
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55 expert telephone support. The telephone support consisted of three short sessions (one  
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3 30 minute session followed by two 15 minute sessions) and was delivered by  
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5 audiological scientists who received standardised training in delivering the telephone  
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7 therapy. A treatment manual was followed during the telephone sessions, and  
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9 focussed on ensuring the VR programme was implemented appropriately. Therapists  
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11 also elicited and addressed participant concerns, and agreed goals. Follow-up sessions  
12  
13 primarily focussed on encouraging adherence to the programme, and discussing  
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15 barriers to adherence. Results from the trial found that both the booklet only and  
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17 booklet with telephone support groups had significantly improved vertigo symptoms  
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19 compared to the routine care group at one year follow-up. Both treatment groups were  
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21 also found to be highly cost-effective.  
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26 Recent years have seen an increasing focus on the patient experience of treatments  
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28 and management of audiological conditions [24], although no research to date has  
29  
30 assessed participants' experiences of self-management of dizziness. This study aims  
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32 to evaluate participants' experience of using booklet-based VR alone, or with expert  
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34 telephone support in order to improve understanding of the experience of these  
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36 models of dizziness self-management.  
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## 43 **METHOD**

### 44 **Study design**

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46 This study used qualitative, semi-structured interviews to explore participant  
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48 experiences of dizziness self-management using booklet-based VR alone or with  
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50 telephone support.  
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### Participants and sampling

Approval for this study was granted by the National Research Ethics Service.

Participants were a subgroup of participants taking part in the previously mentioned VR trial of self-management of dizziness [22]. Information about this study was included in the information sheet participants received in their invitation pack to take part in the VR trial. Consent for this study was included on the VR trial consent form, and it was made clear that participation was voluntary and would not affect participation in the VR trial. Recruitment was managed by an independent administrator, and interviewing took place within a couple of months of participating in the VR trial.

Initially consecutive sampling of participants who completed VR therapy was used. Participants were also sampled towards the end of the trial after the therapists had become more experienced in delivering the treatment. Purposive sampling was used towards the end of recruitment to ensure adequate representation of male participants. Recruitment continued until the data reached saturation and no new codes emerged. The sample consisted of 10 men and 23 women between the ages of 27 and 84 ( $M = 59.3$ ,  $SD = 14.27$ ). Fifteen Participants (6 men, 9 women) were in the booklet only condition and eighteen participants (4 men, 14 women) were in the booklet and telephone support condition.

### Procedure

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 Semi-structured telephone interviews were conducted by the first author (IM) and a  
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5 female post-graduate health psychology trainee. Both researchers had limited  
6  
7 knowledge of dizziness aetiology and treatments. The interview schedule is displayed  
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9 in Figure 1.  
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16 [insert Figure 1]  
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23 Before commencing the interview, the researcher spent a few minutes explaining that  
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25 the study aimed to understand participants' experiences of the treatment they received,  
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27 and it was emphasised that there were no right or wrong answers and that the  
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29 interviewer was not involved in designing the clinical trial. It was hoped that this  
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31 would minimise participants giving socially desirable responses such as being overly  
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33 positive about their treatment.  
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41 The semi-structured interview schedule included a number of broad, open-ended  
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43 questions with follow-up prompts. Interviews began by asking participants what they  
44  
45 expected from the VR trial and moved towards discussing their experiences of the  
46  
47 treatment, such as specific elements they found helpful or unhelpful. An inductive  
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49 approach was taken, so the interview schedule was used to guide, rather than dictate  
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51 the interviews. The course of the interview was often tailored according to  
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53 participants' responses in an attempt to explore topics spontaneously raised by the  
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3 participant. The interviews lasted between 9 and 47 minutes ( $M = 18.27$  minutes,  $SD$   
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5  $= 8.47$ ).  
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### 10 11 **Qualitative Analysis** 12

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15 Analysis of interview transcripts was carried out by the first author using an inductive  
16  
17 thematic analysis where dominant themes were identified through close examination  
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19 of the data [25]. Interview recordings were listened to several times, and interview  
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21 transcripts were read and re-read to ensure a high level of familiarity with the data.  
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29 Firstly, open coding was carried out on 6 interview transcripts and an initial coding  
30  
31 schedule was devised in order to clearly define each emerging theme. The coding  
32  
33 manual was then revised throughout the coding of the remaining transcripts. The  
34  
35 original codes were frequently combined or divided into further codes depending on  
36  
37 the emergent findings. Themes were continually compared with newly coded  
38  
39 interview transcripts to ensure that they were readily applied to the data by using the  
40  
41 researcher's familiarity with the text and coding manual to frequently assess and  
42  
43 reassess how codes were being applied to the raw data. The coding manual was  
44  
45 discussed within the research team, and final amendments were made. The final  
46  
47 coding manual was then applied to all transcripts. The analysis process was carried  
48  
49 out systematically, with category agreement being obtained at each stage of analysis  
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51 and inter-rater agreement between the first and second authors obtained for the final  
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53 coded data. To maintain anonymity, interview data were labelled by participant  
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3 number, gender and treatment group (BO for booklet only and B+TS to indicate  
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5 booklet with telephone support condition).  
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## 11 RESULTS

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15 Analysis of 33 interview transcripts identified 3 overarching categories and 11  
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17 primary themes. The theme labels and their organisation are depicted in Figure 2.  
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19 While many of these themes were common amongst most participants, the variety of  
20  
21 themes reflects individual differences in the experience of chronic dizziness and  
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23 therapy. Despite two populations being interviewed (booklet only and booklet with  
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25 telephone support); the majority of the themes and sub-themes arose from both groups,  
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27 albeit in different contexts.  
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41 The identified themes can be organised into three main categories: 1) living with  
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43 dizziness prior to the VR therapy; 2) experiences of therapy, and 3) therapy barriers  
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45 and impact. Due to the limited scope of this paper, the results will be presented in  
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47 terms of these three broader categories. Supporting interview quotations are provided.  
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### 55 Living with dizziness prior to VR therapy

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Several participants from both treatment groups described the practical ways in which their dizziness symptoms had affected their day-to-day lives. Dizziness was described as having major and often devastating consequences on participants' lives in terms of disruption to daily tasks.

Participants also described the emotional impact suffering from dizziness had on them. Some mentioned feeling depressed and “pulled down” by their dizziness, while others mentioned feeling anxious and frightened by attacks of dizziness.

*“I can get up in the mornings and be fine and suddenly it might come on, and the minute it comes on I'm... it makes me feel miserable and depressed, you know. And I'm frightened how long it's going to last... I can't drive, I can't go to the shops, I've got to just wait and see how long. Sometimes I might have it a day; sometimes I might have it for weeks. So, yeah, it can really pull you down because you don't want to do anything, you don't want to bend over and do anything, you don't want to look up or you can't read a book, um watch telly, or do anything, knitting, computer work, you can't do anything, you've just got to sit and wait for it to sort itself out. So it really pulls you down.” (26, female, BO)*

Participants discussed prior medical treatments and consultations for dizziness. Many participants had encountered problems in gaining a diagnosis or treatment, with pharmacological treatments often described as ineffective.

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5 *"I was glad to have it because I knew that there was something out there like this [VR*  
6 *exercises], but like I said I went to my doctor and got no joy from him about it... I had*  
7 *read things and it said there was nothing they could do, you know. The tablets don't*  
8 *really work when they give them to you. Just gave me a headache."* (26, female, BO)  
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17 Some participants described their belief that there are no existing treatments for  
18 dizziness, while others spoke of how healthcare professionals had told them there are  
19 no available treatments and that they should learn to live with the condition.  
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### 28 **Experiences of therapy**

29  
30 The majority of participants described the VR booklet as being easy to understand and  
31 follow, with many describing the educational and informative nature of the booklet as  
32 helpful for increasing understanding of their condition.  
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40 Participants found the exercise instructions clear, and were generally surprised by  
41 how gentle and easy to follow VR exercises were. Participants in the telephone  
42 support condition discussed their experiences of doing the exercises after having a  
43 telephone support session. Participants mentioned feeling encouraged to increase the  
44 intensity of the exercises, and felt that the exercises were tailored to their individual  
45 needs following the telephone support session.  
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2  
3 *“Well if she had gone through something with me then it would be a little bit more*  
4  
5 *um.. refined to suit my particular needs, should I say.” (14, female, B+TS)*  
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12 A large proportion of participants in the telephone support group mentioned their  
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14 progress being monitored and receiving advice and health information during the  
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16 telephone session. Health information largely related to causes of dizziness and  
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18 explanations of the way in which VR exercises retrain the balance system, which  
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20 participants found helpful.  
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28 Several participants mentioned that they would have benefited from extra telephone  
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30 support sessions as they felt these had a motivational effect and helped them adhere to  
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32 the exercises. Participants mentioned feeling more focussed and determined to follow  
33  
34 the exercise regime properly following the support session.  
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40 *“I was finding that the problems that I experienced day to day were diminishing, and*  
41  
42 *I guess there might have been a tendency not to sort of finish the thing properly, if I*  
43  
44 *hadn't had the phone calls.” (27, male, B+TS)*  
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51 All participants in the telephone support condition discussed the relationship with  
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53 their therapist. Participants described their therapists as being easy to talk to, which  
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55 made them feel at ease and that this contributed to their enjoyment of the telephone  
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57 sessions.  
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5 *"I liked the manner of the people concerned and the fact that they didn't talk down.*  
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7 *They weren't overly officious and medical in any way, so you didn't feel you were*  
8 *..um.. talking to someone who knew a lot more than you did. But they put you at ease.*  
9 *It was very nice."* (1, female, B+TS)

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Having a good relationship with the therapist was discussed as a key element to feeling supported. One participant described how the extra support, encouragement and monitoring helped her adhere to the exercise programme when she considered giving up.

31 *"I think that just the fact that there was some support when I was sort of thinking, oh*  
32 *you know, I don't know if I want to do this. Just having somebody ring just to say you*  
33 *are doing really well, just carry on and I'll speak to you again in a couple of weeks."*  
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(20, female, B+TS)

Participants mentioned feeling reassured, encouraged and empowered following their telephone session. Some participants discussed feeling as if their therapist genuinely cares about them and their well-being. Participants mentioned their therapist being someone they could laugh with, someone who is willing to listen to them and understands their problems.

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*“Well, yes it was quite nice. It was almost like a friend calling each time, you know, to see how I was getting on, and she was very pleased and I was very pleased.” (14, female, B+TS)*

### Therapy barriers and impact

Participants discussed factors affecting their adherence to the VR exercise programme.

While some participants mentioned stopping the exercises early when their symptoms improved, the main reason participants gave for not adhering to the programme was that the exercises induced dizziness and often worsened their symptoms to start with.

The vast majority of participants who reported adherence problems as a result of inducing dizziness, or after their symptoms improved, were in the booklet only condition.

*“And maybe, maybe I’m just a bit of a wuss and I just gave up after 6-8 weeks. And maybe if I could keep going it would have helped me. I just, me personally, it was making me feel so nauseous for the rest of the day, I couldn’t. And I did try the exercises at different times of day to see if I could work out a better time to do it, and that, you know, wasn’t really any good.” (5, female, BO)*

Changes since taking part in the VR trial were discussed by all participants. These included changes to their emotional states, physical condition and social lives. Many

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3 participants mentioned that their dizziness symptoms had improved since undertaking  
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5 the VR exercise programme, this included participants from both treatment groups.  
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11 *“Well, it’s changed my life. I couldn’t believe that such simple exercises could make*  
12 *such a difference to my balance, and the dizzy feeling, because I used to have them*  
13 *during the week, and I don’t have them anymore. Having done the exercises, It*  
14 *doesn’t happen. So.. you know, for me it’s wonderful.” (16, female, B+TS)*  
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21 Many participants, from both treatment groups, mentioned feeling more confident  
22 since following the VR exercise programme, especially in terms of doing physical  
23 activities they previously would have avoided. Participants also discussed how the VR  
24 trial affected their emotional well-being. They mentioned feeling less stressed in their  
25 everyday lives, and this was linked to other health benefits, such as suffering fewer  
26 headaches. Participants also reported feeling less anxious about their dizziness,  
27 attributing this to increased understanding about their condition. Participants  
28 mentioned feeling less nervous of having a dizzy spell as they felt more capable of  
29 managing the symptoms. They also mentioned suffering less anxiety in their everyday  
30 lives as they now understood that it is not their behaviour that causes dizziness.  
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50 *“I’m not so frightened by it I suppose, actually in a way. Much calmer about the*  
51 *whole thing.” (14, female, B+TS)*  
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3 Participants from both treatment groups discussed how the trial helped them to realise  
4 they're not alone in suffering from dizziness. Participants talked about the reassurance  
5 and confidence they got from realising that there are many other sufferers of dizziness.  
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7 A couple of younger participants described the relief they felt when they realised it is  
8 not uncommon for people their age to suffer from dizziness, despite the condition  
9 often being thought of as only affecting older people. Participants also mentioned  
10 feeling reassured and comforted in the knowledge that there are researchers and  
11 healthcare professionals looking for more effective treatments for dizziness.  
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24 *“But to know that there are people out there trying to help us get rid of this gives you*  
25 *a boost, really gives you a boost, you know, you don't feel so alone, because there is*  
26 *nobody else around me that suffers with this. So you know, oh mum's got one of her*  
27 *giddy heads, you know? And it just makes you feel absolutely crap.” (26, female, BO)*  
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38 Participants talked about feeling more supported by the people close to them, and  
39 believed this was a result of their loved ones having an increased awareness and  
40 understanding of dizziness after reading the trial materials. It was reported that this  
41 support and understanding gave participants more confidence in undertaking activities  
42 that they normally would have avoided.  
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53 *“So you know, some of my responses to things, for example things I would have*  
54 *avoided doing because I would have felt I'm going to fall over or something. I am not*  
55 *so risk adverse to some of things because I know I've got people that understand what*  
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3 *I suffer from and are going to be able to help me and not allow me to fall, so overall I*  
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5 *guess what I'm trying to say is that I don't tend to avoid doing some of the things that*  
6  
7 *I think I would have done, because I would have been too afraid that I might have*  
8  
9 *fallen over or something. I'm not allowing the dizziness to really impact you know, my*  
10  
11 *quality of life and things that." (8, female, B+TS)*  
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## 14 15 16 **DISCUSSION**

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21 The majority of participants reported a positive experience of VR therapy, whether it involved  
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23 using the booklet alone or accompanied by telephone support. Participants found the booklet  
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25 easy to understand and follow, and were surprised by how simple and gentle the exercises  
26  
27 were. Many participants also discussed improvements in their dizziness symptoms since  
28  
29 following the VR exercise. These findings suggest booklet-based VR to be an acceptable and  
30  
31 valued model of delivering VR.  
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35  
36 Participants who received telephone support found the therapist's comments and suggestions  
37  
38 reassuring, encouraging and motivational and believed their therapist cared about them and  
39  
40 their rehabilitation, which was regarded as a major element of feeling supported. Many  
41  
42 participants felt that a genuine relationship developed between them and their therapist over  
43  
44 the three sessions. This is consistent with previous therapeutic alliance research which  
45  
46 suggests the therapeutic relationship is established within the first three sessions [26, 27].  
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49  
50 Similar findings were reported in a study evaluating patient-centred audiological  
51  
52 rehabilitation in older adults with hearing aids [28]. Patients identified a strong therapeutic  
53  
54 relationship as the heart of their audiological rehabilitation, and described trust, joint decision-  
55  
56 making and the importance of being listened to as key factors in the maintenance of this  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 relationship. A mixed-methods interaction analysis of the telephone support sessions for  
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5 patients with chronic dizziness supported these findings by identifying patient-centred  
6  
7 communication to be related to the therapeutic relationship [29].  
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10  
11 There were some indications that telephone support might encourage better adherence to the  
12  
13 VR programme. Many participants described the support of their therapist and the positive  
14  
15 attitude of their therapist towards their progress as being a key element in their perseverance  
16  
17 with the exercises. Lack of adherence in the booklet only group was most commonly  
18  
19 explained by fear of inducing dizziness symptoms. In contrast to the booklet only group,  
20  
21 participants who received the telephone support were given the opportunity to discuss their  
22  
23 concerns with a VR therapist who was able to provide advice and allay fears that the exercises  
24  
25 were damaging their balance system. The VR trial results [22] found adherence to the full  
26  
27 programme of exercises was reported by 44% of participants from the booklet with telephone  
28  
29 support group compared to only 34% of participants in the booklet only group, although this  
30  
31 group difference did not reach statistical significance. However, exploratory retrospective  
32  
33 analyses found that participants from the telephone support group reported carrying out the  
34  
35 exercises with greater intensity compared to the booklet only group.  
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### 43 **Strengths and limitations**

44  
45 A limitation of this research is that the sample inevitably comprises only those people willing  
46  
47 to be interviewed, and is therefore likely to be non-representative of the trial population. In  
48  
49 particular, those who appreciated the therapy and the telephone support may well be over-  
50  
51 represented. However, several aspects of this research give confidence that the results reflect  
52  
53 the participants' experiences of self-managing rehabilitation for chronic dizziness. Thematic  
54  
55 analysis is a rigorous systematic approach to qualitative analysis, and the inductive approach  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 taken allows the findings of this study to be grounded in the data rather than being drawn  
4  
5 from previous theories. The consecutive sampling methodology, managed by an independent  
6  
7 administrator, allowed this study to include participants receiving telephone support from  
8  
9 therapists at different stages in the RCT, and therefore varying degrees of experience in this  
10  
11 particular setting. Recruitment continued until the data reached saturation, after which  
12  
13 emerging theories were thoroughly explored through theoretical sampling allowing a varied  
14  
15 sample to be included in this study. Interviewing took place within a couple of months of  
16  
17 participants completing the 12 week treatment programme to ensure the experience of therapy  
18  
19 was recent and fresh in participants' minds, a particularly important issue when dealing with  
20  
21 elderly participants. While this approach was preferable, a longer delay between therapy and  
22  
23 interviewing might have yielded an insight into long-term effects and lasting changes.  
24  
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### 30 **Clinical and research implications**

31  
32 Participants felt that a genuine relationship developed between them and their therapist in  
33  
34 three short sessions. This highlights the potential benefit that minimal remote contact can  
35  
36 have on participants' engagement in self-management programmes. The telephone based  
37  
38 method of delivering therapy did not appear to negatively impact the popularity of the  
39  
40 treatment, and may in fact be preferred by many patients with dizziness as previous research  
41  
42 has found this patient group to be reluctant to travel for treatment [30]. Telephone delivered  
43  
44 therapy is a fast-growing, cost-effective method of delivering therapy and might be  
45  
46 particularly beneficial for use in elderly or disabled patients.  
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### 52 *Contributorship statement*

53 All authors were involved in the study design and analysis. The majority of interviews and  
54  
55 initial coding of the data were conducted by IM. SK provided inter-rater agreement for all  
56  
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Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
final coded data, and LY provided category agreement at each stage of data analysis. All  
authors were involved in the writing and preparation of this manuscript.

#### *Competing interests*

The authors report no conflicts of interest.

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#### *Data sharing statement*

No additional data available

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Interview schedule: qualitative evaluation study

1. First of all, can you start by telling me what you were expecting from the self-treatment booklet?
1. *What were you expecting from the telephone support?*
2. How did you find the self-treatment booklet overall?
3. *How did you find the telephone support overall?*
4. What problems (if any) did you come across using the self-treatment booklet?
5. *What problems (if any) did you come across having the telephone support?*
6. Can you tell me what you liked about the self-treatment booklet?
7. *Can you tell me what you liked about the telephone support?*
8. Can you tell me what concerns you have about the self-treatment booklet?
9. *Can you tell me what concerns you have about the telephone support?*
10. Tell me about anything that you feel has changed from using the self-treatment booklet?
11. *Tell me about anything that you feel has changed from having the telephone support sessions?*
12. Do you have anything else you would like to tell me about your experiences of the self treatment booklet that we haven't already covered?
13. *Do you have anything else you would like to tell me about your experiences of the telephone support that we haven't already covered?*

**Figure 1.** Semi-structured interview schedule - Italics indicating questions for participants from the telephone support group only.

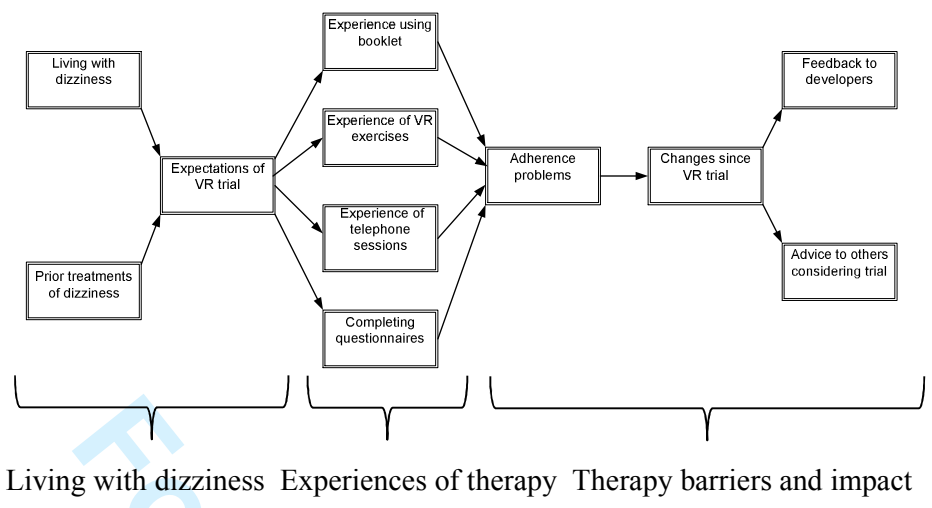


Figure 2. Diagram of Themes and Sub-Themes

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# BMJ Open

## Understanding patient experiences of using booklet-based vestibular rehabilitation with or without remote support for self-managing chronic dizziness.

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<b>Primary Subject Heading</b>:	Qualitative research
Secondary Subject Heading:	Ear, nose and throat/otolaryngology, Patient-centred medicine, Rehabilitation medicine
Keywords:	Telemedicine < BIOTECHNOLOGY & BIOINFORMATICS, Audiology < OTOLARYNGOLOGY, PRIMARY CARE, QUALITATIVE RESEARCH

SCHOLARONE™  
Manuscripts

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

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5 **Manuscript title:** Understanding patient experiences of using booklet-based  
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7 vestibular rehabilitation with or without remote support for self-managing chronic  
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9 dizziness.  
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32 **Keywords:** dizziness, vestibular rehabilitation, telephone support, qualitative  
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36 **Word count:** 4251  
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Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

## ABSTRACT:

**Objective:** This study explores participants' experience of self-management of dizziness using booklet-based vestibular rehabilitation (VR) with or without expert telephone support. **Design:** Semi-structured qualitative interviews were conducted. **Setting:** Participants were recruited from primary care practices as part of a large RCT. **Participants:** Interviews were carried out with 33 people self-managing chronic dizziness using booklet based vestibular rehabilitation with or without expert telephone support. **Results:** Data were analysed using inductive thematic analysis. The majority of participants in both groups reported a positive experience of VR therapy, with many participants reporting an improvement in dizziness symptoms since undertaking the therapy. Participants in the telephone support group felt that a genuine relationship developed between them and their therapist within three short sessions, and described their therapy sessions as reassuring, encouraging and motivational. **Conclusions:** The VR treatment booklet appears to be a valued tool for self-managing chronic dizziness and people appreciate receiving remote telephone support.

**Trial registration:** ClinicalTrials.gov NCT00732797.

### Strengths and limitations of this study

- Thematic analysis is a rigorous systematic approach to qualitative analysis.
- Recruitment continued until the data reached saturated.
- This study was nested within a RCT and explores patient experiences of the therapy.
- The sample inevitably comprises only of those people willing to be interviewed, and it is therefore possible that those who appreciated the therapy may be over-represented.

Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

## INTRODUCTION

Chronic dizziness is a common symptom, and is believed to affect up to 25% of the community [1]. Suffering from chronic dizziness can be debilitating and lead to loss of independence, reduced fitness, falls and fear of falling [2]. Qualitative studies have highlighted the impact of dizziness on everyday life, often leading to poor function and disability [3, 4]. Dizziness is more common in older people, but it is estimated that one in ten working age adults suffer some degree of disability due to dizziness [5]. Significant disability, medication use and medical consultations due to dizziness have been found in more than 20% of people over the age of 60 [6], with 24% of dizziness being attributed to vestibular disorder [7].

The vast majority of people suffering from dizziness consult their General Practitioner (GP) in the first instance [7]. Dizziness is commonly encountered in primary care. It is estimated that 2% of all primary care consultations are for dizziness [6, 8], with this figure increasing to as high as 30% in people over 65 years of age [9]. The majority of patients with dizziness seen in primary care have peripheral vestibular disorder (including benign paroxysmal positional vertigo (BPPV), vestibular neuritis and Ménière's disease), and serious sinister pathology in patients with no other symptoms is very rare [10, 11, 12].

Primary care patients with dizziness are typically treated and managed with reassurance and medication to relieve their symptoms [13, 14]. Reviews of the management of chronic dizziness have, however, concluded that no medication has well established efficacy in the treatment of dizziness, nor is any suitable for long-

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 term use [11, 15]. Furthermore, many patients with chronic dizziness have needs that  
4  
5 are not being met by healthcare [3]. Vestibular Rehabilitation (VR) is now the  
6  
7 recommended treatment for dizziness [15, 16]. The central component of VR is a  
8  
9 programme of graded exercises consisting of eye, head and body movements designed  
10  
11 to stimulate the vestibular system and promote neurological adaptation [14]. VR  
12  
13 exercises typically induce dizziness symptoms to start with, but repetition for several  
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15 weeks generally results in partial or complete resolution of symptoms [17, 18].  
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17 However, very few patients with chronic dizziness currently have access to VR  
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19 therapy, as referral to specialist clinics where VR is typically delivered can be lengthy  
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21 and expensive [19, 20].  
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27 Yardley and colleagues [21] developed a booklet teaching home-based VR exercises  
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29 for the self-management of dizziness. The booklet was designed to promote adherence  
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31 to VR and address cognitive and behavioural factors that may contribute to the high  
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33 rates of psychological problems known to commonly accompany vestibular  
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35 dysfunction [22]. VR elements of the treatment booklet is discussed in the main trial  
36  
37 paper [23]. This booklet has been evaluated in several clinical trials, and has been  
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39 found to be a safe, effective, and cost-effective treatment for dizziness [21, 23, 24].  
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### 45 **Study context**

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49 This study was nested within a VR trial of booklet-based self-management of  
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51 dizziness in primary care [23]. VR trial participants were randomised to either a  
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53 routine care group, booklet only group or booklet with telephone support group. The  
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55 trial used the self-treatment VR booklet [21] to evaluate the cost-effectiveness of two  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 models of VR delivery for people with dizziness: booklet only and booklet with  
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5 expert telephone support. Results from the trial found that both the booklet only and  
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7 booklet with telephone support groups had significantly improved vertigo symptoms  
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9 compared to the routine care group at one year follow-up. Both treatment groups were  
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11 also found to be highly cost-effective [23].  
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16 Incorporating qualitative work in clinical trials is an import part of person-based  
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18 intervention development [25], helping understand participants' experiences and  
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20 acceptability of the therapy. Recent years have seen an increasing focus on the patient  
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22 experience of treatments and management of audiological conditions [26], although  
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24 no research to date has assessed participants' experiences of self-management of  
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26 dizziness. This study aims to understand participants' experience of using booklet-  
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28 based VR alone, or with expert telephone support in order to improve understanding  
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30 of the experience of these models of dizziness self-management and their  
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32 acceptability for implementation.  
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## 40 **METHOD**

### 41 **Study design**

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43 This study used qualitative, semi-structured interviews to explore and understand  
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45 participant experiences of dizziness self-management using booklet-based VR alone  
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47 or with telephone support.  
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### 52 **Telephone support**

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Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

The telephone support consisted of three short sessions (one 30 minute session followed by two 15 minute sessions) and was delivered by audiological scientists who received standardised training in delivering the telephone therapy. A treatment manual was followed during the telephone sessions, and focussed on ensuring the VR programme was implemented appropriately. Therapists also elicited and addressed participant concerns, and agreed goals. Follow-up sessions primarily focussed on encouraging adherence to the programme, and discussing barriers to adherence.

### **Participants and sampling**

Approval for this study was granted by the National Research Ethics Service. Participants were a subgroup of participants taking part in the previously mentioned VR trial of self-management of dizziness [23]. Information about this study was included in the information sheet participants received in their invitation pack to take part in the VR trial. Consent for this study was included on the VR trial consent form, and it was made clear that participation was voluntary and would not affect participation in the VR trial. Recruitment was managed by an independent administrator, and interviewing took place within a couple of months of participating in the VR trial.

Initially consecutive sampling of participants who completed VR therapy was used. Participants were also sampled towards the end of the trial after the therapists had become more experienced in delivering the treatment. Purposive sampling was used towards the end of recruitment to ensure adequate representation of male participants. Recruitment continued until the data reached saturation and no new codes emerged.

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 The sample consisted of 10 men and 23 women between the ages of 27 and 84 (M =  
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5 59.3, SD = 14.27). Fifteen Participants (6 men, 9 women) were in the booklet only  
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7 condition and eighteen participants (4 men, 14 women) were in the booklet and  
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9 telephone support condition. Participants were invited onto the trial because they had  
10  
11 a diagnosis of vestibular dizziness. Symptom severity was measured by the Vertigo  
12  
13 Symptom Scale – Short Form [27] as part of the VR trial. 10 Participants were high  
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15 symptom severity (2 booklet only; 8 booklet and telephone support) and 23  
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17 participants were low symptom severity (13 booklet only; 10 booklet and telephone  
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19 support).  
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### 31 Procedure

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34 Semi-structured telephone interviews were conducted between March 2010 and  
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36 March 2011 by the first author (IM) and another female post-graduate health  
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38 psychology trainee. Both researchers had limited knowledge of dizziness aetiology  
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40 and treatments. The interview schedule is displayed in Figure 1.  
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54 Before commencing the interview, the researcher spent a few minutes explaining that  
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56 the study aimed to understand participants' experiences of the treatment they received,  
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3 and it was emphasised that there were no right or wrong answers and that the  
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5 interviewer was not involved in designing the clinical trial. It was hoped that this  
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7 would minimise participants giving socially desirable responses such as being overly  
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9 positive about their treatment.  
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16 The semi-structured interview schedule included 14 broad, open-ended questions with  
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18 follow-up prompts. Interviews began by asking participants what they expected from  
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20 the VR trial and moved towards discussing participants' experiences of the treatment.  
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22 An inductive approach was taken, so the interview schedule was used to guide, rather  
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24 than dictate the interviews. The course of the interview was often tailored according  
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26 to participants' responses in an attempt to explore topics spontaneously raised by the  
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28 participant. The interviews lasted between 9 and 47 minutes ( $M = 18.27$  minutes,  $SD$   
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30  $= 8.47$ ). Interview transcripts were transcribed verbatim by an independent  
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32 administrator.  
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### 41 **Qualitative Analysis**

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44 Analysis of interview transcripts was carried out by IM using an inductive thematic  
45  
46 analysis where dominant themes were identified through close examination of the data  
47  
48 [28]. Interview recordings were listened to several times, and interview transcripts  
49  
50 were read and re-read to ensure a high level of familiarity with the data.  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 Firstly, open coding was carried out on 6 interview transcripts and an initial coding  
4  
5 schedule was devised in order to clearly define each emerging theme. The coding  
6  
7 manual was then revised throughout the coding of the remaining transcripts. The  
8  
9 original codes were frequently combined or divided into further codes depending on  
10  
11 the emergent findings [28]. Themes were continually compared with newly coded  
12  
13 interview transcripts to ensure that they were readily applied to the data by using the  
14  
15 researcher's familiarity with the text and coding manual to frequently assess and  
16  
17 reassess how codes were being applied to the raw data. The coding manual was  
18  
19 discussed within the research team, and final amendments were made. The final  
20  
21 coding manual was then applied to all transcripts. The analysis process was carried  
22  
23 out systematically, with category agreement being obtained at each stage of analysis  
24  
25 and inter-rater agreement between authors IM and SK obtained for the final coded  
26  
27 data. To maintain anonymity, interview data were labelled by participant number,  
28  
29 gender and treatment group (BO for booklet only and B+TS to indicate booklet with  
30  
31 telephone support condition).  
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## 41 RESULTS

42  
43 Analysis of 33 interview transcripts identified 3 main themes and 11 sub-themes. The  
44  
45 themes, sub-themes and key content are depicted in Figure 2, highlighting the main  
46  
47 group differences and similarities.. Despite two populations being interviewed  
48  
49 (booklet only and booklet with telephone support); the majority of the themes and  
50  
51 sub-themes arose from both groups, albeit in different contexts.  
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3 [insert Figure 2]  
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10 The identified themes can be organised into three main themes: 1) living with  
11 dizziness prior to the VR therapy; 2) experiences of therapy, and 3) therapy barriers  
12 and impact. Due to the limited scope of this paper, the results will be presented in  
13 terms of these three themes. Supporting interview quotations are provided.  
14  
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### 20 21 22 23 **Living with dizziness prior to VR therapy** 24

25  
26 Participants were not explicitly asked about their experiences of living with dizziness,  
27 yet most participants spontaneously spoke about this during the interview. Several  
28 participants from both treatment groups described the practical ways in which their  
29 dizziness symptoms had affected their day-to-day lives. Dizziness was described as  
30 having major and often devastating consequences on participants' lives in terms of  
31 disruption to daily tasks.  
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44 Participants also described the emotional impact suffering from dizziness had on them.  
45  
46 Some talked about feeling depressed and “pulled down” by their dizziness, while  
47  
48 others mentioned feeling anxious and frightened by attacks of dizziness.  
49  
50

51  
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53  
54 *“I can get up in the mornings and be fine and suddenly it might come on, and the*  
55 *minute it comes on I'm... it makes me feel miserable and depressed, you know. And*  
56  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 *I'm frightened how long it's going to last... I can't drive, I can't go to the shops, I've*  
4 *got to just wait and see how long. Sometimes I might have it a day; sometimes I might*  
5 *have it for weeks. So, yeah, it can really pull you down because you don't want to do*  
6 *anything, you don't want to bend over and do anything, you don't want to look up or*  
7 *you can't read a book, um watch telly, or do anything, knitting, computer work, you*  
8 *can't do anything, you've just got to sit and wait for it to sort itself out. So it really*  
9 *pulls you down.” (26, female, BO)*  
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23 Participants discussed prior medical treatments and consultations for dizziness. Many  
24 participants had encountered problems in gaining a diagnosis or treatment, with  
25 pharmacological treatments often described as ineffective.  
26  
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29  
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31  
32

33 *“I was glad to have it because I knew that there was something out there like this [VR*  
34 *exercises], but like I said I went to my doctor and got no joy from him about it... I had*  
35 *read things and it said there was nothing they could do, you know. The tablets don't*  
36 *really work when they give them to you. Just gave me a headache.” (26, female, BO)*  
37  
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45 Some participants described their belief that there are no existing treatments for  
46 dizziness, while others spoke of how healthcare professionals had told them there are  
47 no available treatments and that they should learn to live with the condition.  
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## 56 Experiences of therapy

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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

2  
3 The majority of participants described the VR booklet as being easy to understand and  
4  
5 follow, with many describing the educational and informative nature of the booklet as  
6  
7 helpful for increasing understanding of their condition.  
8  
9

10  
11  
12 *“I felt encouraged [through reading the booklet]. I thought, I’ve got to take this on*  
13  
14 *and er.. keep going with it.” (17, male, BO)*  
15

16  
17  
18  
19  
20  
21 Participants found the exercise instructions clear, and were generally surprised by  
22  
23 how gentle and easy to follow VR exercises were.  
24

25  
26 *“Well, it was so easy to do. You know, there was nothing ...nothing that I couldn’t er..*  
27  
28 *do, or wouldn’t do.” (7, male, BO)*  
29

30  
31  
32 Participants in the telephone support condition discussed their experiences of doing  
33  
34 the exercises after having a telephone support session. Participants described feeling  
35  
36 encouraged to increase the intensity of the exercises, and felt that the exercises were  
37  
38 tailored to their individual needs following the telephone support session.  
39

40  
41  
42  
43  
44 *“Well if she had gone through something with me then it would be a little bit more*  
45  
46 *um.. refined to suit my particular needs, should I say.” (14, female, B+TS)*  
47  
48

49  
50  
51  
52  
53 A large proportion of participants in the telephone support group mentioned their  
54  
55 progress being monitored and receiving advice and health information during the  
56  
57 telephone session. Health information largely related to causes of dizziness and  
58  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 explanations of the way in which VR exercises retrain the balance system, which  
4  
5 participants found helpful.  
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10  
11 Several participants in the telephone support group thought that they would have  
12 benefited from extra telephone support sessions as they felt these had a motivational  
13 effect and helped them adhere to the exercises. Participants described feeling more  
14 focussed and determined to follow the exercise regime properly following the support  
15 session.  
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26 *“I was finding that the problems that I experienced day to day were diminishing, and*  
27 *I guess there might have been a tendency not to sort of finish the thing properly, if I*  
28 *hadn’t had the phone calls.” (27, male, B+TS)*  
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38 All participants in the telephone support condition discussed the relationship with  
39 their therapist. Participants described their therapists as being easy to talk to, which  
40 made them feel at ease and that this contributed to their enjoyment of the telephone  
41 sessions.  
42  
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50 *“I liked the manner of the people concerned and the fact that they didn’t talk down.*  
51 *They weren’t overly officious and medical in any way, so you didn’t feel you were*  
52 *..um.. talking to someone who knew a lot more than you did. But they put you at ease.*  
53 *It was very nice.” (1, female, B+TS)*  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

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5  
6 Having a good relationship with the therapist was discussed as a key element to  
7  
8 feeling supported. One participant described how the extra support, encouragement  
9  
10 and monitoring helped her adhere to the exercise programme when she considered  
11  
12 giving up.  
13

14  
15  
16  
17  
18 *“I think that just the fact that there was some support when I was sort of thinking, oh*  
19  
20 *you know, I don’t know if I want to do this. Just having somebody ring just to say you*  
21  
22 *are doing really well, just carry on and I’ll speak to you again in a couple of weeks.”*  
23  
24 *(20, female, B+TS)*  
25  
26  
27

28  
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31  
32 Participants talked about feeling reassured, encouraged and empowered following  
33  
34 their telephone session. Some participants discussed feeling as if their therapist  
35  
36 genuinely cares about them and their well-being. Participants described their therapist  
37  
38 being someone they could laugh with, someone who is willing to listen to them and  
39  
40 understands their problems.  
41  
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47  
48 *“Well, yes it was quite nice. It was almost like a friend calling each time, you know, to*  
49  
50 *see how I was getting on, and she was very pleased and I was very pleased.” (14,*  
51  
52 *female, B+TS)*  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

2  
3 **Therapy barriers and impact**

4  
5  
6 Participants discussed factors affecting their adherence to the VR exercise programme.

7  
8 While some participants mentioned stopping the exercises early when their symptoms  
9 improved, the main reason participants gave for not adhering to the programme was  
10 that the exercises induced dizziness and often worsened their symptoms to start with.

11  
12 Some participants also mentioned difficulties increasing the intensity of the exercises.

13  
14  
15 The vast majority of participants who reported adherence problems as a result of  
16 inducing dizziness, or after their symptoms improved, were in the booklet only  
17 condition.  
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26  
27 *“And maybe, maybe I’m just a bit of a wuss and I just gave up after 6-8 weeks. And*  
28 *maybe if I could keep going it would have helped me. I just, me personally, it was*  
29 *making me feel so nauseous for the rest of the day, I couldn’t. And I did try the*  
30 *exercises at different times of day to see if I could work out a better time to do it, and*  
31 *that, you know, wasn’t really any good.” (5, female, BO)*  
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43 Changes since taking part in the VR trial were discussed by all participants. These  
44 included emotional, physical and social changes. Many participants felt that their  
45 dizziness symptoms had improved since undertaking the VR exercise programme, this  
46 included participants from both treatment groups.  
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49  
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53  
54  
55 *“Well, it’s changed my life. I couldn’t believe that such simple exercises could make*  
56 *such a difference to my balance, and the dizzy feeling, because I used to have them*  
57  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 *during the week, and I don't have them anymore. Having done the exercises, It*  
4  
5 *doesn't happen. So.. you know, for me it's wonderful."* (16, female, B+TS)  
6  
7  
8  
9

10  
11 Many participants, from both treatment groups, described feeling more confident  
12 since following the VR exercise programme, especially in terms of doing physical or  
13 social activities they previously would have avoided.  
14  
15

16  
17  
18  
19 *"I was going down the town on my own...I wasn't thinking 'oh should I do that?'.  
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60*  
*Where now... I feel actually a little bit different, this might be really sad but I feel a  
bit different when I am walking. I feel as if my brain is in touch with my feet a little bit  
more."* (28, female, BO)

Participants also discussed how the VR trial affected their emotional well-being. They mentioned feeling less stressed in their everyday lives, and this was linked to other health benefits, such as suffering fewer headaches. Participants also reported feeling less anxious about their dizziness, attributing this to increased understanding about their condition. Participants described feeling less nervous of having a dizzy spell as they felt more capable of managing the symptoms. They also mentioned suffering less anxiety in their everyday lives as they now understood that it is not their behaviour that causes dizziness.

*"I'm not so frightened by it I suppose, actually in a way. Much calmer about the  
whole thing."* (14, female, B+TS)

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5  
6 Participants from both treatment groups discussed how the trial helped them to realise  
7 they're not alone in suffering from dizziness. Participants talked about the reassurance  
8 and confidence they got from realising that there are many other sufferers of dizziness.  
9  
10 A couple of younger participants described the relief they felt when they realised it is  
11 not uncommon for people their age to suffer from dizziness, despite the condition  
12 often being thought of as only affecting older people. Participants also mentioned  
13 feeling reassured and comforted in the knowledge that there are researchers and  
14 healthcare professionals looking for more effective treatments for dizziness.  
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27 *“But to know that there are people out there trying to help us get rid of this gives you*  
28 *a boost, really gives you a boost, you know, you don't feel so alone, because there is*  
29 *nobody else around me that suffers with this. So you know, oh mum's got one of her*  
30 *giddy heads, you know? And it just makes you feel absolutely crap.” (26, female, BO)*  
31  
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41 Participants talked about feeling more supported by the people close to them, and  
42 believed this was a result of their loved ones having an increased awareness and  
43 understanding of dizziness after reading the trial materials. It was reported that this  
44 support and understanding gave participants more confidence in undertaking activities  
45 that they normally would have avoided.  
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*“So you know... things I would have avoided doing because I would have felt I’m going to fall over or something... I am not so risk adverse to some things because I know I’ve got people that understand what I suffer from and are going to be able to help me and not allow me to fall, so overall I guess what I’m trying to say is that I don’t tend to avoid doing some of the things that I think I would have done, because I would have been too afraid that I might have fallen over or something. I’m not allowing the dizziness to really impact you know, my quality of life and things that.”*  
(8, female, B+TS)

## DISCUSSION

This study aimed to understand participants’ experience of using booklet-based VR alone or with expert telephone support for dizziness self-management. The majority of participants reported a positive experience of VR therapy, whether it involved using the booklet alone or accompanied by telephone support. Participants found the booklet easy to understand and follow, and were surprised by how simple and gentle the exercises were. Many participants also discussed improvements in their dizziness symptoms since following the VR exercise. Participants describe feeling more confident, empowered, less anxious, and more supported by family and friends. Participants also discussed partaking in social and physical activities that they could not previously do. These findings suggest booklet-based VR to be an acceptable and valued model of delivering VR.

Participants who received telephone support found the therapist’s comments and suggestions reassuring, encouraging and motivational and believed their therapist cared about them and

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2  
3 their rehabilitation, which was regarded as a major element of feeling supported. Many  
4  
5 participants felt that a genuine relationship developed between them and their therapist over  
6  
7 the three sessions. This is consistent with previous therapeutic alliance research which  
8  
9 suggests the therapeutic relationship is established within the first three sessions [29, 30].  
10  
11 Similar findings were reported in a study evaluating patient-centred audiological  
12  
13 rehabilitation in older adults with hearing aids [31]. Patients identified a strong therapeutic  
14  
15 relationship as the heart of their audiological rehabilitation, and described trust, joint decision-  
16  
17 making and the importance of being listened to as key factors in the maintenance of this  
18  
19 relationship. A mixed-methods interaction analysis of the telephone support sessions for  
20  
21 patients with chronic dizziness supported these findings by identifying patient-centred  
22  
23 communication to be related to the therapeutic relationship [32].  
24  
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29  
30 There were some indications that telephone support might encourage better adherence to the  
31  
32 VR programme. Many participants described the support of their therapist and the positive  
33  
34 attitude of their therapist towards their progress as being a key element in their perseverance  
35  
36 with the exercises. Lack of adherence in the booklet only group was most commonly  
37  
38 explained by fear of inducing dizziness symptoms. In contrast to the booklet only group,  
39  
40 participants who received the telephone support were given the opportunity to discuss their  
41  
42 concerns with a VR therapist who was able to provide advice and allay fears that the exercises  
43  
44 were damaging their balance system. The VR trial results [23] found adherence to the full  
45  
46 programme of exercises was reported by 44% of participants from the booklet with telephone  
47  
48 support group compared to only 34% of participants in the booklet only group, although this  
49  
50 group difference did not reach statistical significance. However, exploratory retrospective  
51  
52 analyses found that participants from the telephone support group reported carrying out the  
53  
54 exercises with greater intensity compared to the booklet only group.  
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Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

### **Strengths and limitations**

A limitation of this research is that the sample inevitably comprises only those people willing to be interviewed, and is therefore likely to be non-representative of the trial population. In particular, those who appreciated the therapy and the telephone support may well be over-represented. However, several aspects of this research give confidence that the results reflect the participants' experiences of self-managing rehabilitation for chronic dizziness. Thematic analysis is a rigorous systematic approach to qualitative analysis, and the inductive approach taken allows the findings of this study to be grounded in the data rather than being drawn from previous theories. The consecutive sampling methodology, managed by an independent administrator, allowed this study to include participants receiving telephone support from therapists at different stages in the RCT, and therefore varying degrees of experience in this particular setting. Recruitment continued until the data reached saturation, after which emerging theories were thoroughly explored through theoretical sampling allowing a varied sample to be included in this study. Interviewing took place within a couple of months of participants completing the 12 week treatment programme to ensure the experience of therapy was recent and fresh in participants' minds, a particularly important issue when dealing with elderly participants. While this approach was preferable, a longer delay between therapy and interviewing might have yielded an insight into long-term effects and lasting changes.

### **Clinical and research implications**

Booklet-based VR has previously been found to be a cost-effective model of VR delivery [23], and the current findings suggest it to also be acceptable and valued by patients with chronic dizziness. Participants in the telephone support group felt that a genuine relationship developed between them and their therapist in three short sessions. This highlights the

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 potential benefit that minimal remote contact can have on participants' engagement in self-  
4  
5 management programmes. The telephone based method of delivering therapy did not appear  
6  
7 to negatively impact the popularity of the treatment, and may in fact be preferred by many  
8  
9 patients with dizziness as previous research has found this patient group to be reluctant to  
10  
11 travel for treatment [33]. Telephone delivered therapy is a fast-growing, cost-effective method  
12  
13 of delivering therapy and might be particularly beneficial for use in elderly or disabled  
14  
15 patients.  
16  
17  
18  
19

#### 20 21 *Contributorship statement*

22 All authors were involved in the study design and analysis. The majority of interviews and  
23  
24 initial coding of the data were conducted by IM. SK provided inter-rater agreement for all  
25  
26 final coded data, and LY provided category agreement at each stage of data analysis. All  
27  
28 authors were involved in the writing and preparation of this manuscript.  
29  
30  
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#### 33 34 *Competing interests*

35  
36 The authors report no conflicts of interest.  
37  
38  
39

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43  
44 commercial or not-for-profit sectors  
45  
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#### 49 50 *Data sharing statement*

51 No additional data available  
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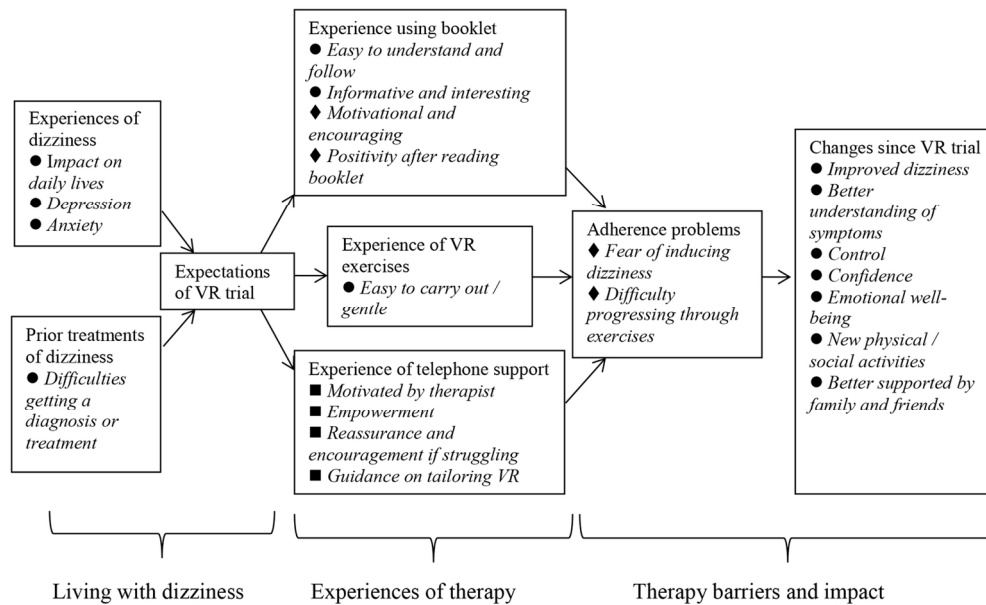
	<u>Interview schedule: qualitative evaluation study</u>
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**Interview schedule: qualitative evaluation study**

1. First of all, can you start by telling me what you were expecting from the self-treatment booklet?
2. *What were you expecting from the telephone support?*
3. How did you find the self-treatment booklet overall?
4. *How did you find the telephone support overall?*
5. What problems (if any) did you come across using the self-treatment booklet?
6. *What problems (if any) did you come across having the telephone support?*
7. Can you tell me what you liked about the self-treatment booklet?
8. *Can you tell me what you liked about the telephone support?*
9. Can you tell me what concerns you have about the self-treatment booklet?
10. *Can you tell me what concerns you have about the telephone support?*
11. Tell me about anything that you feel has changed from using the self-treatment booklet?
12. *Tell me about anything that you feel has changed from having the telephone support sessions?*
13. Do you have anything else you would like to tell me about your experiences of the self treatment booklet that we haven't already covered?
14. *Do you have anything else you would like to tell me about your experiences of the telephone support that we haven't already covered?*

**Figure 1.** Semi-structured interview schedule - Italics indicating questions for participants from the telephone support group only.

160x117mm (300 x 300 DPI)



**Figure 2.** Diagram of themes, sub-themes and key content

● = Content from both treatment groups; ◆ = Content mainly from booklet-only group; ■ = Content mainly from Booklet with telephone support group

141x115mm (300 x 300 DPI)

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE**

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Page 7
3. Occupation	What was their occupation at the time of the study?	Page 7
4. Gender	Was the researcher male or female?	Page 7
5. Experience and training	What experience or training did the researcher have?	Both researchers received interview training
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	No
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page 8
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Page 7
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis, Page 9
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Consecutive and purposive sampling, Page 7
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Mail and telephone, Page 6



12. Sample size	How many participants were in the study?	33, Page 10
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Telephone interviews, Page 7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Methods, Page 7-8
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods, Page 8
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods, Page 9
20. Field notes	Were field notes made during and/or after the inter view or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	Methods, Page 8
22. Data saturation	Was data saturation discussed?	Methods, Page 7
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Methods, Page 9
25. Description of the coding tree	Did authors provide a description of the coding tree?	Results, Page 10
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods, Page 8
27. Software	What software, if applicable, was used to manage the data?	maxQDA
28. Participant checking	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results, Pages 10-18
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results, Page 10
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results

Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process,

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For peer review only

# BMJ Open

## Understanding patient experiences of self-managing chronic dizziness: a qualitative study of booklet-based vestibular rehabilitation with or without remote support.

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2015-007680.R2
Article Type:	Research
Date Submitted by the Author:	24-Apr-2015
Complete List of Authors:	Muller, Ingrid; University of Southampton, Department of Psychology Kirby, Sarah; University of Southampton, Department of Psychology Yardley, Lucy; University of Southampton, Department of Psychology
<b>Primary Subject Heading</b>:	Qualitative research
Secondary Subject Heading:	Ear, nose and throat/otolaryngology, Patient-centred medicine, Rehabilitation medicine
Keywords:	Telemedicine < BIOTECHNOLOGY & BIOINFORMATICS, Audiology < OTOLARYNGOLOGY, PRIMARY CARE, QUALITATIVE RESEARCH

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Manuscripts

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

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5 **Manuscript title:** Understanding patient experiences of self-managing chronic  
6 dizziness: a qualitative study of booklet-based vestibular rehabilitation with or  
7 without remote support.  
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14 **Authors:** Ingrid Muller, University of Southampton, Southampton, UK

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32 **Keywords:** dizziness, vestibular rehabilitation, telephone support, qualitative  
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Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

## ABSTRACT:

**Objective:** This study explores participants' experience of self-management of dizziness using booklet-based vestibular rehabilitation (VR) with or without expert telephone support. **Design:** Semi-structured qualitative interviews were conducted. **Setting:** Participants were recruited from primary care practices as part of a large RCT. **Participants:** Interviews were carried out with 33 people (10 men and 23 women, aged 27 to 84) self-managing chronic dizziness using booklet based vestibular rehabilitation with or without expert telephone support. **Results:** Data were analysed using inductive thematic analysis. The majority of participants in both groups reported a positive experience of VR therapy, with many participants reporting an improvement in dizziness symptoms since undertaking the therapy. Participants in the telephone support group felt that a genuine relationship developed between them and their therapist within three short sessions, and described their therapy sessions as reassuring, encouraging and motivational. **Conclusions:** The VR treatment booklet appears to be a valued tool for self-managing chronic dizziness and people appreciate receiving remote telephone support.

**Trial registration:** ClinicalTrials.gov NCT00732797.

### Strengths and limitations of this study

- Thematic analysis is a rigorous systematic approach to qualitative analysis.
- Recruitment continued until the data reached saturated.
- This study was nested within a RCT and explores patient experiences of the therapy.
- The sample inevitably comprises only of those people willing to be interviewed, and it is therefore possible that those who appreciated the therapy may be over-represented.

Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

## INTRODUCTION

Chronic dizziness is a commonly experienced symptom, and is believed to affect up to 25% of the community [1]. Suffering from chronic dizziness can be debilitating and lead to loss of independence, reduced fitness, falls and fear of falling [2]. Qualitative studies have highlighted the impact of dizziness on everyday life, often leading to poor function and disability [3, 4]. Dizziness is more common in older people, but it is estimated that one in ten working age adults suffer some degree of disability due to dizziness [5]. Significant disability, medication use and medical consultations due to dizziness have been found in more than 20% of people over the age of 60 [6], with 24% of dizziness being attributed to vestibular disorder [7].

The vast majority of people suffering from dizziness consult their General Practitioner (GP) in the first instance [7]. It is estimated that 2% of all primary care consultations are for dizziness [6, 8], with this figure increasing to as high as 30% in people over 65 years of age [9]. The majority of patients experiencing dizziness symptoms have peripheral vestibular disorder (including benign paroxysmal positional vertigo (BPPV), vestibular neuritis and Ménière's disease), and serious sinister pathology in patients with no other symptoms is rare [10, 11, 12].

Primary care patients with dizziness are typically treated and managed with reassurance and medication to relieve their symptoms [13, 14]. Reviews of the management of chronic dizziness have, however, concluded that no medication has well established efficacy in the treatment of dizziness, nor is any suitable for long-term use [11, 15]. Furthermore, many patients with chronic dizziness have unmet

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2 healthcare needs [3]. Vestibular Rehabilitation (VR) is now the recommended  
3 treatment for dizziness [15, 16]. The central component of VR is a programme of  
4 graded exercises consisting of eye, head and body movements designed to stimulate  
5 the vestibular system and promote neurological adaptation [14]. VR exercises  
6 typically induce dizziness symptoms to start with, but repetition for several weeks  
7 generally results in partial or complete resolution of symptoms [17, 18]. However,  
8 few patients with chronic dizziness currently have access to VR therapy, as referral to  
9 specialist clinics where VR is typically delivered can be lengthy and expensive [19,  
10 20].

11 Yardley and colleagues [21] developed a booklet teaching home-based VR exercises  
12 for the self-management of dizziness. The booklet was designed to promote adherence  
13 to VR and address cognitive and behavioural factors that may contribute to the high  
14 rates of psychological problems known to commonly accompany vestibular  
15 dysfunction [22]. VR elements of the treatment booklet is discussed in the main trial  
16 paper [23]. This booklet has been evaluated in several clinical trials, and has been  
17 found to be a safe, effective, and cost-effective treatment for dizziness [21, 23, 24].

### 18 **Study context**

19 This study was nested within a VR trial of booklet-based self-management of  
20 dizziness in primary care [23]. VR trial participants were randomised to either a  
21 routine care group, booklet only group or booklet with telephone support group. The  
22 trial used the self-treatment VR booklet [21] to evaluate the cost-effectiveness of two  
23 models of VR delivery for people with dizziness: booklet only and booklet with  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 telephone support. Results from the trial found that both the booklet only and booklet  
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5 with telephone support groups had significantly improved vertigo symptoms  
6  
7 compared to the routine care group at one year follow-up. Both treatment models  
8  
9 were also found to be highly cost-effective [23].  
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14 Incorporating qualitative work in clinical trials is an important part of person-based  
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16 intervention development [25], helping understand participants' experiences and  
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18 acceptability of the therapy. In recent years there has been an increasing focus on the  
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20 patient experience of treatments and management of audiological conditions [26],  
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22 although no research to date has assessed participants' experiences of self-  
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24 management of dizziness. This study aims to understand participants' experience of  
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26 using booklet-based VR alone, or with telephone support in order to improve  
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28 understanding of the experience of these models of dizziness self-management.  
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## 35 **METHOD**

### 36 37 38 **Study design**

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40 This study used qualitative, semi-structured interviews to explore and understand  
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42 participant experiences of dizziness self-management using booklet-based VR alone  
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44 or with telephone support.  
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### 49 **Telephone support**

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51 The telephone support consisted of three short sessions (one 30 minute session  
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53 followed by two 15 minute sessions) that was delivered by audiological scientists who  
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55 received standardised training in delivering the telephone therapy. A treatment manual  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2 was followed during the telephone sessions, and focussed on ensuring the VR  
3 programme was implemented appropriately. Therapists also elicited and addressed  
4 participant concerns, and agreed on goals. Follow-up sessions primarily focussed on  
5 encouraging adherence to the programme, and discussing barriers to adherence.  
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### 11 **Participants and sampling**

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14 Approval for this study was granted by the National Research Ethics Service.  
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16 Participants were a subgroup of participants taking part in the previously mentioned  
17 VR trial of self-management of dizziness [23]. Participants were invited to take part in  
18 the trial if they had a diagnosis or treatment for dizziness in the past 12 months.  
19  
20 Eligibility of potential participants was assessed at baseline to ensure participants  
21 were currently experiencing dizziness symptoms. Information about this study was  
22 included in the information sheet participants received in their invitation pack to take  
23 part in the VR trial. Consent for this study was included on the VR trial consent form,  
24 and it was made clear that participation was voluntary and would not affect  
25 participation in the VR trial. Recruitment was managed by an independent  
26 administrator, and interviewing took place within a couple of months of participating  
27 in the VR trial.  
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48 Initially consecutive sampling of participants who completed VR therapy was used.  
49 Participants were also sampled towards the end of the trial after the therapists had  
50 become more experienced in delivering the treatment. Purposive sampling was used  
51 towards the end of recruitment to ensure adequate representation of male participants.  
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53 Recruitment continued until the data reached saturation and no new codes emerged.  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 The sample consisted of 10 men and 23 women between the ages of 27 and 84 (M =  
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5 59.3, SD = 14.27). Fifteen participants (6 men, 9 women) were in the booklet only  
6  
7 condition and eighteen participants (4 men, 14 women) were in the booklet and  
8  
9 telephone support condition. Participants were invited onto the trial because they had  
10  
11 a diagnosis of vestibular dizziness. Symptom severity was measured by the Vertigo  
12  
13 Symptom Scale – Short Form [27] as part of the VR trial. Ten participants had high  
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15 symptom severity (2 booklet only; 8 booklet and telephone support) and 23  
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17 participants were low symptom severity (13 booklet only; 10 booklet and telephone  
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19 support).  
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## 27 Procedure

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30 Semi-structured telephone interviews were conducted between March 2010 and  
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32 March 2011 by the first author (IM) and another female post-graduate health  
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34 psychology trainee. Both researchers had limited knowledge of dizziness aetiology  
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36 and treatments. The interview schedule is displayed in Figure 1.  
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44 [insert Figure 1]  
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51 Before commencing the interview, the researcher spent a few minutes explaining that  
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53 the study aimed to understand participants' experiences of the treatment they received,  
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55 and it was emphasised that there were no right or wrong answers and that the  
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57 interviewer was not involved in designing the clinical trial. It was hoped that this  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 would minimise participants giving socially desirable responses such as being overly  
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5 positive about their treatment.  
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11 The semi-structured interview schedule included 14 broad, open-ended questions with  
12 follow-up prompts. Interviews began by asking participants what they expected from  
13 the VR trial and moved towards discussing participants' experiences of the treatment.  
14 An inductive approach was taken, so the interview schedule was used to guide, rather  
15 than dictate the interviews. The course of the interview was often tailored according  
16 to participants' responses in an attempt to explore topics spontaneously raised by the  
17 participant. The interviews lasted between 9 and 47 minutes (M = 18.27 minutes, SD  
18 = 8.47). Interview transcripts were transcribed verbatim by an independent  
19 administrator.  
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### 37 **Qualitative Analysis**

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39 Analysis of interview transcripts was carried out by IM using an inductive thematic  
40 analysis where dominant themes were identified through close examination of the data  
41 [28]. Interview recordings were listened to several times, and interview transcripts  
42 were read and re-read to ensure a high level of familiarity with the data.  
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53 Firstly, open coding was carried out on six interview transcripts using maxQDA  
54 software and an initial coding schedule was devised in order to clearly define each  
55 emerging theme. The coding manual was then revised throughout the coding of the  
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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2 remaining transcripts. The original codes were frequently combined or divided into  
3 further codes depending on the emergent findings [28]. Themes were continually  
4 compared with newly coded interview transcripts to ensure that they were readily  
5 applied to the data by using the researcher's familiarity with the text and coding  
6 manual to frequently assess and reassess how codes were being applied to the raw  
7 data. The coding manual was discussed within the research team, and final  
8 amendments were made. The final coding manual was then applied to all transcripts.  
9 The analysis process was carried out systematically, with category agreement being  
10 obtained at each stage of analysis and inter-rater agreement between authors IM and  
11 SK obtained for the final coded data. To maintain anonymity, interview data were  
12 labelled by participant number, gender and treatment group (BO for booklet only and  
13 B+TS to indicate booklet with telephone support condition).

## 34 RESULTS

37 Analysis of 33 interview transcripts identified three main themes and eight sub-  
38 themes. The themes, sub-themes and key content are depicted in Figure 2,  
39 highlighting the main group differences and similarities. The majority of the themes  
40 and sub-themes arose from both groups (booklet only and booklet with telephone  
41 support), albeit in different contexts.

52 [insert Figure 2]

Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

The identified themes can be organised into three main themes: 1) living with dizziness prior to the VR therapy; 2) experiences of therapy, and 3) therapy barriers and impact. Due to the limited scope of this paper, the results will be presented in terms of these three themes. Supporting interview quotations are provided.

### **Living with dizziness prior to VR therapy**

#### *Experiences of dizziness*

Participants were not explicitly asked about their experiences of living with dizziness, yet most participants spontaneously spoke about this during the interview. Several participants from both treatment groups described the practical ways in which their dizziness symptoms had affected their day-to-day lives. Dizziness was described as having major and often devastating consequences on participants' lives in terms of disruption to daily tasks.

Participants also described the emotional impact suffering from dizziness had on them. Some talked about feeling depressed and “pulled down” by their dizziness, while others mentioned feeling anxious and frightened by attacks of dizziness.

*“I can get up in the mornings and be fine and suddenly it might come on, and the minute it comes on I'm... it makes me feel miserable and depressed, you know. And I'm frightened how long it's going to last... I can't drive, I can't go to the shops, I've got to just wait and see how long. Sometimes I might have it a day; sometimes I might*

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
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3 *have it for weeks. So, yeah, it can really pull you down because you don't want to do*  
4  
5 *anything, you don't want to bend over and do anything, you don't want to look up or*  
6  
7 *you can't read a book, um watch telly, or do anything, knitting, computer work, you*  
8  
9 *can't do anything, you've just got to sit and wait for it to sort itself out. So it really*  
10  
11 *pulls you down.” (26, female, BO)*

#### 14 *Prior treatments of dizziness*

15  
16  
17  
18 Participants discussed prior medical treatments and consultations for dizziness. Many  
19  
20 participants had encountered problems in gaining a diagnosis or treatment, with  
21  
22 pharmacological treatments often described as ineffective.  
23  
24  
25  
26  
27

28  
29 *“I was glad to have it because I knew that there was something out there like this [VR*  
30  
31 *exercises], but like I said I went to my doctor and got no joy from him about it... I had*  
32  
33 *read things and it said there was nothing they could do, you know. The tablets don't*  
34  
35 *really work when they give them to you. Just gave me a headache.” (26, female, BO)*  
36  
37  
38  
39  
40

41 Some participants described their belief that there are no existing treatments for  
42  
43 dizziness, while others spoke of how healthcare professionals had told them there are  
44  
45 no available treatments and that they should learn to live with the condition.  
46

47  
48 *“When I went to the hospital... I'd felt a little bit, oh well that's it, you know, this is*  
49  
50 *what's wrong and you're going to have to live with it, sort of thing, which is not a*  
51  
52 *very caring feeling.” ( 14, female, B+TS)*  
53  
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56

#### 57 **Experiences of therapy**

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1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

2  
3 *Experience using booklet*

4 The majority of participants described the VR booklet as being easy to understand and  
5  
6 follow, with many describing the educational and informative nature of the booklet as  
7  
8 helpful for increasing understanding of their condition.  
9

10  
11  
12  
13  
14 *“I felt encouraged [through reading the booklet]. I thought, I’ve got to take this on*  
15  
16 *and er.. keep going with it.” (17, male, BO)*

17  
18  
19  
20 *Experience of VR exercises*

21  
22  
23 Participants found the exercise instructions clear, and were generally surprised by  
24  
25 how gentle and easy to follow VR exercises were.  
26

27  
28  
29 *“Well, it was so easy to do. You know, there was nothing ...nothing that I couldn’t er..*  
30  
31 *do, or wouldn’t do.” (7, male, BO)*

32  
33  
34 Participants in the telephone support condition discussed their experiences of doing  
35  
36 the exercises after having a telephone support session. Participants described feeling  
37  
38 encouraged to increase the intensity of the exercises, and felt that the exercises were  
39  
40 tailored to their individual needs following the telephone support session.  
41

42  
43  
44  
45  
46 *“Well if she had gone through something with me then it would be a little bit more*  
47  
48 *um.. refined to suit my particular needs, should I say.” (14, female, B+TS)*

49  
50  
51  
52 *Experience of telephone support*

53  
54  
55 A large proportion of participants in the telephone support group mentioned their  
56  
57 progress being monitored and receiving advice and health information during the  
58  
59

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 telephone session. Health information largely related to causes of dizziness and  
4  
5 explanations of the way in which VR exercises retrain the balance system, which  
6  
7 participants found helpful.  
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14 Several participants in the telephone support group thought that they would have  
15  
16 benefited from extra telephone support sessions as they felt these had a motivational  
17  
18 effect and helped them adhere to the exercises. Participants described feeling more  
19  
20 focussed and determined to follow the exercise regime properly following the support  
21  
22 session.  
23

24  
25  
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27  
28 *“I was finding that the problems that I experienced day to day were diminishing, and*  
29  
30 *I guess there might have been a tendency not to sort of finish the thing properly, if I*  
31  
32 *hadn't had the phone calls.” (27, male, B+TS)*  
33  
34

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39 All participants in the telephone support condition discussed the relationship with  
40  
41 their therapist. Participants described their therapists as being easy to talk to, which  
42  
43 made them feel at ease and that this contributed to their enjoyment of the telephone  
44  
45 sessions.  
46  
47

48  
49  
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51  
52 *“I liked the manner of the people concerned and the fact that they didn't talk down.*  
53  
54 *They weren't overly officious and medical in any way, so you didn't feel you were*  
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*..um.. talking to someone who knew a lot more than you did. But they put you at ease.*

*It was very nice.” (1, female, B+TS)*

Having a good relationship with the therapist was discussed as a key element to feeling supported. One participant described how the extra support, encouragement and monitoring helped her adhere to the exercise programme when she considered giving up.

*“I think that just the fact that there was some support when I was sort of thinking, oh you know, I don’t know if I want to do this. Just having somebody ring just to say you are doing really well, just carry on and I’ll speak to you again in a couple of weeks.”*

*(20, female, B+TS)*

Participants talked about feeling reassured, encouraged and empowered following their telephone session. Some participants discussed feeling as if their therapist genuinely cares about them and their well-being. Participants described their therapist being someone they could laugh with, someone who is willing to listen to them and understands their problems.

*“Well, yes it was quite nice. It was almost like a friend calling each time, you know, to see how I was getting on, and she was very pleased and I was very pleased.” (14,*

*female, B+TS)*

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## Therapy barriers and impact

### *Adherence problems*

Participants discussed factors affecting their adherence to the VR exercise programme. While some participants mentioned stopping the exercises early when their symptoms improved, the main reason participants gave for not adhering to the programme was that the exercises induced dizziness and often worsened their symptoms to start with. Some participants also mentioned difficulties increasing the intensity of the exercises. The vast majority of participants who reported adherence problems as a result of inducing dizziness, or after their symptoms improved, were in the booklet only condition.

*“And maybe, maybe I’m just a bit of a wuss and I just gave up after 6-8 weeks. And maybe if I could keep going it would have helped me. I just, me personally, it was making me feel so nauseous for the rest of the day, I couldn’t. And I did try the exercises at different times of day to see if I could work out a better time to do it, and that, you know, wasn’t really any good.” (5, female, BO)*

### Changes since VR trial

Changes since taking part in the VR trial were discussed by all participants. These included emotional, physical and social changes. Many participants felt that their dizziness symptoms had improved since undertaking the VR exercise programme, this included participants from both treatment groups.

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*“Well, it’s changed my life. I couldn’t believe that such simple exercises could make such a difference to my balance, and the dizzy feeling, because I used to have them during the week, and I don’t have them anymore. Having done the exercises, It doesn’t happen. So.. you know, for me it’s wonderful.” (16, female, B+TS)*

Many participants, from both treatment groups, described feeling more confident since following the VR exercise programme, especially in terms of doing physical or social activities they previously would have avoided.

*“I was going down the town on my own...I wasn’t thinking ‘oh should I do that?’. Where now... I feel actually a little bit different, this might be really sad but I feel a bit different when I am walking. I feel as if my brain is in touch with my feet a little bit more.” (28, female, BO)*

Participants also discussed how the VR trial affected their emotional well-being. They mentioned feeling less stressed in their everyday lives, and this was linked to other health benefits, such as suffering fewer headaches. Participants also reported feeling less anxious about their dizziness, attributing this to increased understanding about their condition. Participants described feeling less nervous of having a dizzy spell as they felt more capable of managing the symptoms. They also mentioned suffering less anxiety in their everyday lives as they now understood that it is not their behaviour that causes dizziness.

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness

2  
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4  
5 *“I’m not so frightened by it I suppose, actually in a way. Much calmer about the*  
6 *whole thing.” (14, female, B+TS)*  
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14 Participants from both treatment groups discussed how the trial helped them to realise  
15 they're not alone in suffering from dizziness. Participants talked about the reassurance  
16 and confidence they got from realising that there are many other sufferers of dizziness.  
17  
18 A couple of younger participants described the relief they felt when they realised it is  
19 not uncommon for people their age to suffer from dizziness, despite the condition  
20 often being thought of as only affecting older people. Participants also mentioned  
21 feeling reassured and comforted in the knowledge that there are researchers and  
22 healthcare professionals looking for more effective treatments for dizziness.  
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35 *“But to know that there are people out there trying to help us get rid of this gives you*  
36 *a boost, really gives you a boost, you know, you don't feel so alone, because there is*  
37 *nobody else around me that suffers with this.” (26, female, BO)*  
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46 Participants talked about feeling more supported by the people close to them, and  
47 believed this was a result of their loved ones having an increased awareness and  
48 understanding of dizziness after reading the trial materials. It was reported that this  
49 support and understanding gave participants more confidence in undertaking activities  
50 that they normally would have avoided.  
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*“So you know... things I would have avoided doing because I would have felt I’m going to fall over or something... I am not so risk adverse... I know I’ve got people that understand what I suffer from and are going to be able to help me and not allow me to fall,.... I don’t tend to avoid doing some of the things that I think I would have done, because I would have been too afraid that I might have fallen over or something. I’m not allowing the dizziness to really impact you know, my quality of life and things that.” (8, female, B+TS)*

## DISCUSSION

This study aimed to understand participants’ experience of using booklet-based VR alone or with telephone support for dizziness self-management. The majority of participants reported a positive experience of VR therapy, whether it involved using the booklet alone or accompanied by telephone support. Participants found the booklet easy to understand and follow, and were surprised by how simple and gentle the exercises were. Many participants also discussed improvements in their dizziness symptoms since following the VR exercise. Participants described feeling more confident, empowered, less anxious, and more supported by family and friends. Participants also discussed partaking in social and physical activities that they could not previously do. These findings suggest booklet-based VR to be an acceptable and valued model of delivering VR.

Participants who received telephone support found the therapist’s comments and suggestions reassuring, encouraging and motivational and believed their therapist cared about them and

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 their rehabilitation, which was regarded as a major element of feeling supported. Many  
4  
5 participants felt that a genuine relationship developed between them and their therapist over  
6  
7 the three sessions. This is consistent with previous therapeutic alliance research which  
8  
9 suggests the therapeutic relationship is established within the first three sessions [29, 30].  
10  
11 Similar findings were reported in a study evaluating patient-centred audiological  
12  
13 rehabilitation in older adults with hearing aids [31]. Patients identified a strong therapeutic  
14  
15 relationship as the heart of their audiological rehabilitation, and described trust, joint decision-  
16  
17 making and the importance of being listened to as key factors in the maintenance of this  
18  
19 relationship. A mixed-methods interaction analysis of the telephone support sessions for  
20  
21 patients with chronic dizziness supported these findings by identifying patient-centred  
22  
23 communication to be related to the therapeutic relationship [32].  
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30 There were some indications that telephone support might encourage better adherence to the  
31  
32 VR programme. Many participants described the support of their therapist and the positive  
33  
34 attitude of their therapist towards their progress as being a key element in their perseverance  
35  
36 with the exercises. Lack of adherence in the booklet only group was most commonly  
37  
38 explained by fear of inducing dizziness symptoms. In contrast to the booklet only group,  
39  
40 participants who received the telephone support were given the opportunity to discuss their  
41  
42 concerns with a VR therapist who was able to provide advice and allay fears that the exercises  
43  
44 were damaging their balance system. The VR trial results [23] found adherence to the full  
45  
46 programme of exercises was reported by 44% of participants from the booklet with telephone  
47  
48 support group compared to only 34% of participants in the booklet only group, although this  
49  
50 group difference did not reach statistical significance. However, exploratory retrospective  
51  
52 analyses found that participants from the telephone support group reported carrying out the  
53  
54 exercises with greater intensity compared to the booklet only group.  
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### **Strengths and limitations**

A limitation of this research is that the sample inevitably comprises only those people willing to be interviewed, and is therefore likely to be non-representative of the trial population. In particular, those who appreciated the therapy and the telephone support may well be over-represented. However, several aspects of this research give confidence that the results reflect participants' experiences of self-managing rehabilitation for chronic dizziness. Thematic analysis is a rigorous systematic approach to qualitative analysis, and the inductive approach taken allows the findings of this study to be grounded in the data rather than being drawn from previous theories. The consecutive sampling methodology, managed by an independent administrator, allowed this study to include participants receiving telephone support from therapists at different stages in the RCT, and therefore varying degrees of experience in this particular setting. Recruitment continued until the data reached saturation, after which emerging theories were thoroughly explored through theoretical sampling allowing a varied sample to be included in this study. Interviewing took place within a couple of months of participants completing the 12 week treatment programme to ensure the experience of therapy was recent and fresh in participants' minds, a particularly important issue when dealing with elderly participants. While this approach was preferable, a longer delay between therapy and interviewing might have yielded an insight into long-term effects and lasting changes.

### **Clinical and research implications**

Booklet-based VR has previously been found to be a cost-effective model of VR delivery [23], and the current findings suggest it to also be acceptable and valued by patients with chronic dizziness. Telephone support enhanced tailoring the VR therapy to the individual. Participants in the telephone support group felt that a genuine relationship developed between them and

1 Muller. Patient Experiences of Self-Managing Chronic Vestibular Dizziness  
2  
3 their therapist in three short sessions. This highlights the potential benefit that minimal remote  
4  
5 contact can have on participants' engagement in self-management programmes. The  
6  
7 telephone based method of delivering therapy did not appear to negatively impact the  
8  
9 popularity of the treatment, and may in fact be preferred by many patients with dizziness as  
10  
11 previous research has found this patient group to be reluctant to travel for treatment [33].  
12  
13 Telephone delivered therapy is a fast-growing, cost-effective method of delivering therapy  
14  
15 and might be particularly beneficial for use in elderly or disabled patients.  
16  
17  
18  
19

#### 20 21 *Contributorship statement*

22 All authors were involved in the study design and analysis. The majority of interviews and  
23  
24 initial coding of the data were conducted by IM. SK provided inter-rater agreement for all  
25  
26 final coded data, and LY provided category agreement at each stage of data analysis. All  
27  
28 authors were involved in the writing and preparation of this manuscript.  
29  
30  
31  
32

#### 33 34 *Competing interests*

35  
36 The authors report no conflicts of interest.  
37  
38  
39

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43  
44 commercial or not-for-profit sectors  
45  
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48

#### 49 50 *Data sharing statement*

51 No additional data available  
52  
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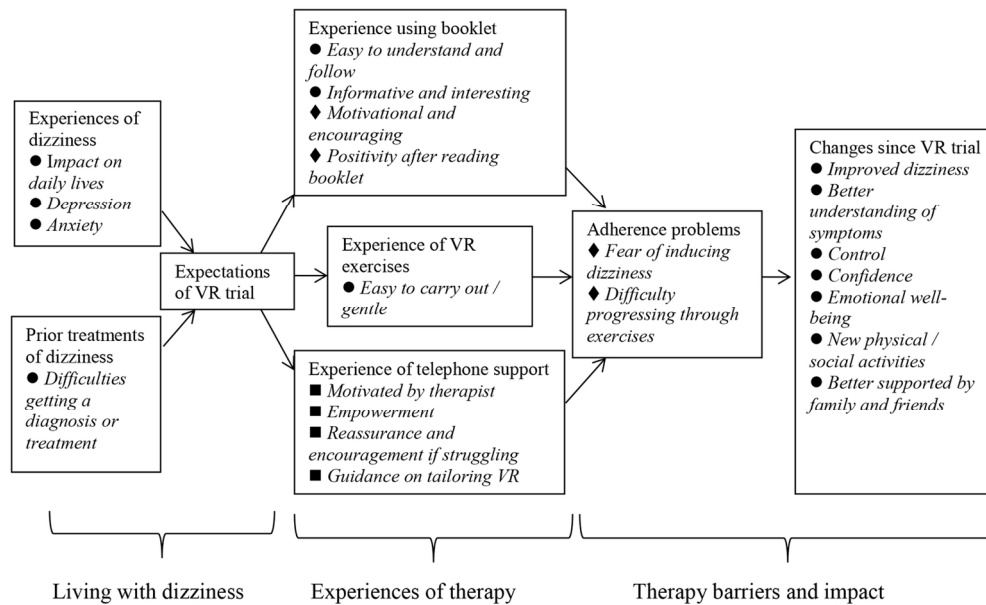
	<u>Interview schedule: qualitative evaluation study</u>
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**Interview schedule: qualitative evaluation study**

1. First of all, can you start by telling me what you were expecting from the self-treatment booklet?
2. *What were you expecting from the telephone support?*
3. How did you find the self-treatment booklet overall?
4. *How did you find the telephone support overall?*
5. What problems (if any) did you come across using the self-treatment booklet?
6. *What problems (if any) did you come across having the telephone support?*
7. Can you tell me what you liked about the self-treatment booklet?
8. *Can you tell me what you liked about the telephone support?*
9. Can you tell me what concerns you have about the self-treatment booklet?
10. *Can you tell me what concerns you have about the telephone support?*
11. Tell me about anything that you feel has changed from using the self-treatment booklet?
12. *Tell me about anything that you feel has changed from having the telephone support sessions?*
13. Do you have anything else you would like to tell me about your experiences of the self treatment booklet that we haven't already covered?
14. *Do you have anything else you would like to tell me about your experiences of the telephone support that we haven't already covered?*

**Figure 1.** Semi-structured interview schedule - Italics indicating questions for participants from the telephone support group only.

160x117mm (300 x 300 DPI)



**Figure 2.** Diagram of themes, sub-themes and key content

● = Content from both treatment groups; ◆ = Content mainly from booklet-only group; ■ = Content mainly from Booklet with telephone support group

141x115mm (300 x 300 DPI)

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE**

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Page 7
3. Occupation	What was their occupation at the time of the study?	Page 7
4. Gender	Was the researcher male or female?	Page 7
5. Experience and training	What experience or training did the researcher have?	Both researchers received interview training
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	No
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page 8
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Page 7
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis, Page 9
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Consecutive and purposive sampling, Page 7
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Mail and telephone, Page 6



12. Sample size	How many participants were in the study?	33, Page 10
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Telephone interviews, Page 7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Methods, Page 7-8
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods, Page 8
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods, Page 9
20. Field notes	Were field notes made during and/or after the inter view or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	Methods, Page 8
22. Data saturation	Was data saturation discussed?	Methods, Page 7
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Methods, Page 9
25. Description of the coding tree	Did authors provide a description of the coding tree?	Results, Page 10
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods, Page 8
27. Software	What software, if applicable, was used to manage the data?	maxQDA
28. Participant checking	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results, Pages 10-18
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results, Page 10
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results

Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process,

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3 please select the file type: *Checklist*. You will NOT be able to proceed with  
4 submission unless the checklist has been uploaded. Please DO NOT include this  
5 checklist as part of the main manuscript document. It must be uploaded as a  
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