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"Football Memories: Impact of non-pharmacologic treatments on Alzheimer's and Dementia sufferers"

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FOOTBALL MEMORIES: IMPACT OF NON-PHARMACOLOGICAL TREATMENTS ON ALZHEIMER'S AND DEMENTIA SUFFERERS

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Dementia prevalence in Scotland is increasing, with 93,282 people currently living with a formal diagnosis (1). Given the ageing population, this is expected to increase to 164,000 by the year 2036 (2).This is emphasising a need for additional ways to treat and manage dementia which focus on improving the quality of life of those living with the disease and relieving the burden that dementia has on their relatives and carers. Increasingly, this type of informal caregiving is becoming a norm (3). This can have negative consequences on caregivers emotionally and physically; where perhaps the greater burden that results from a dementia diagnosis is upon the patients' informal caregivers rather than the person living with the disease (3) (4).

Dementia is a progressive disease causing loss of intellectual function, short term memory, communication and cognitive function (5). Research by Cotelli has highlighted that dementia sufferers retain memory of events and experiences from the past(long term memory) which can be used as targets for interventions in dementia treatment as reminiscence therapy (6) .

There is a seeming lack of stimulation in care home environments for dementia patients, which, according to Kitwood (1990) leads to worsening of the patient's dementia symptomology, more so than the natural course of the disease alone (7). Scotland's National dementia strategy 2017-2020 emphasises the need for increased investment in local dementia care to bridge the gap between policy and

person-centred care (8). The recent SIGN (Scottish Intercollegiate Guidelines Network) guidelines also outline the need for more stimulating care environments for dementia sufferers (5). Reminiscence therapy has been suggested as a possible psychological intervention that can be used in dementia care. 'Football Memories Scotland' reminiscence therapy is an example of a community project which aims to tackle this deficit in stimulating care environments and support dementia friendly communities (8). Although a systematic review by Woods and Subramanian 2012 revealed that it could enhance mood, wellbeing and some aspects of cognitive function (9), there is conflicting evidence regarding the efficacy of reminiscence therapy in dementia patients, with many studies identifying only small effects on cognition, mood and communication (10) (11) (12). This is due to the variability in protocols of reminiscence therapy and a lack of structured and standardised approaches to the reminiscence as a robust therapy for use in dementia care.

Football Memories Reminiscence Therapy

"Football Memories Scotland" was established by Scottish Football Museum and the Scottish Football Heritage Network in 2009 and aimed to trigger fond memories of the 1960s Scottish Football culture in dementia sufferers (12). Its effectiveness was evaluated by Schofield et al.(2010) who concluded that using skilled facilitators to engage male dementia sufferers in a discussion about their football past times, prompted by photographs and memorabilia was the most effective way of improving outcomes in participants with dementia and their carers (11). This was followed by a study by Watchman and Tolson et al.(2015) who concluded that football reminiscence increased sociability and enjoyment in dementia participants, however transport to the sessions and poor facilitation were detrimental to its success. Both studies suggested that football reminiscence is superior to generic reminiscence

methods, such as life-story reviews and individual therapy in those with interest in football (11) (13). This project aims to expand on the research by Schofield(2010) and Watchman and Tolson(2015) and:

i) Assess, from a carers perspective, the impact Football Memories reminiscence therapy has on mood, communication and alertness of those with dementia
ii) Assess the impact it has on respite, mood and quality of life of the carer
iii) Explore the potential barriers that exist for both participants and their carers to attending Football Memories sessions.

Few studies have explored Scottish Football as a medium for the reminiscence. The results of this research will contribute to the current evidence base behind the use of “Football Memoires Scotland” reminiscence therapy as a pioneering psychological treatment for dementia.

Methodology

Watchman and Tolson used a qualitative mixed method approach which identified patterns and themes from a range of documentary evidence (13). A similar approach has been taken for this project. It uses a combined qualitative and quantitative method due to the variability in the facilitation, location and structure of the football memories sessions. This allows the project to exploit the strengths and reduce the limitations of each method on its own (14).

We chose the cares/relatives of people with dementia who participate in Football Memories as the main subjects and sources of data, where two different Football Memories groups were selected at random. This purposive sampling allowed broader understanding of the views of carers from different backgrounds, care home

staff can give their perspectives alongside relatives who are full time carers at home (15). This is similar to the sampling use by Carone, Tischler and Dening(2016) (16). The willing carers from each of the two different Football Memoires groups completed a questionnaire and participated in a focus group discussion with carers and the researcher. The researcher also observed the participants in both Football Memories reminiscence therapy sessions. Each of the selected sessions were led by a facilitator and took place in a church hall. The reminiscence was prompted by photographs and videos which stimulated group conversation about football among the dementia participants. The sessions lasted 90 minutes, split into 2 halves to mimic a football match.

Data Collection

1.Questionnaire

The questionnaire consisted of 4 sections with 21 questions addressing the 3 aims of the research*;* Section 1, “Background information” asked about the participants’ living circumstances, relationship with carers and frequency of attendance. Section 2 asked questions about the participants’ mood which were adapted from subjective and clinical mood impression scales. The Neuropsychiatric Inventory, DMAS, CES-D scale and the Cornell scale for depression were each considered when modelling the question on mood (17) (18) (19).The final question was more similar to the Cornell scale since it asked for “an informants” perspective, like that of the carers in this research (19). It asked the carer to rate if aspects of the participant’s mood had improved, stayed the same or worsened as a result of football memoires, including changes in: Happiness, Calmness, Stress, Agitation and Anger. These methods have been used by Hsieh et al.(2010) to assess mood in dementia patients (20).

Section 3 used a 5-point Likert scale which asked carers to compare communication levels in the participant during football memories to their normal levels. This was adapted from 2 different communication assessment scales used in dementia; The Clinical Dementia rating scale and The Holden Communication Scale (21). Section4 asked carers to comment on their own levels of mood, quality of life and respite, and how these changed in Football Memories. It also asked carers to tick the factors preventing them from attending sessions. 35 carers completed the questionnaire, 25 were completed remotely online and 10 responses were filled out by hand. All 35 were processed together in Microsoft Excel for analysis. The questionnaire took, on average 12 minutes to complete. Most responders were the wives of the participants, who also acted as their main carer.

1. **Focus group discussions**

Focus group discussions were used to assess all three aims of this project. They yielded rich evidence about the attitudes/opinions of the carers who could comment on the effects of the Football Memories therapy. This presented the possibility of exposing dimensions of the therapy which wouldn't be discovered in face to face interviews and questionnaires alone. Further value came from the carers being able to share views among themselves in an inclusive environment (22). Two focus group discussions took place, they included the carers/relatives of the participants in each of the two selected Football Memories reminiscence therapy sessions and the researcher. The first discussion had two attendees, a wife and a brother of the participants. It lasted 40 minutes and took place in a room adjacent to where the respective Football Memories therapy session was concurrently taking place.10 Questions were asked and, following the first group, some questions were adapted to allow for more open questioning in the second group discussion. This had 9

attendees, all were wives of the participants and lasted 39 minutes. Both focus group discussions were recorded and the audios were transcribed into written data titled “Focus Group 1 and 2”. Throughout both discussions field notes were documented to enhance the transparency of the evidence collection and to reduce bias (23).

2. Observation

Following each focus group discussion with the carers, the Football Memories reminiscence therapy participants were observed. The first was during the second half of the first reminiscence therapy session with two male regular attendees to Football Memories and a facilitator. Active involvement in the session was used to understand the effects of the therapy on the dementia participants first hand; how they engaged with the facilitator, each other and the memorabilia material to explore the first aim of this research (24). The second observation followed Focus Group 2 adapting a different observation to data collection. All 9 participants in the therapy were observed as an outsider and notes were documented about the therapy session. A conversation with the facilitator following the session also provided a new perspective on the impacts of Football Memories. Observation was a useful approach for exploring the first aim since one could understand sessions by applying context to the evidence, such as levels of individual involvement, emotional factors, personal characteristics and how reliant the group are on the facilitators (14).

Coding of Qualitative data

Generating codes from qualitative transcription text ensures recognition of important issues. These codes contribute to the production of themes in a thematic analysis. Braun and Clark describe code generation as an important step within qualitative research methodology (25). Complete coding of the transcribed data from both focus

groups, observation notes and any questionnaire responses written in prose occurred by hand on printed versions of the transcripts (25). Computer technology such as CAQDAS (Computer Assisted Qualitative Data Analysis Software) was considered but this method is subject to incorrect assumptions. Coding was done by highlighting quotes, words or phrases in the transcriptions which either; occurred often, answered the research aims or were important in the eyes of the carer. The phrases, contributing to each code, were given with a Location Tag telling the reader where in the transcribed text the evidence came from, this is explained in **Table 1**.

Each code was numbered and tabulated alongside its location tag and data from the transcription to allow themes to be identified. The use of full transcription and complete coding ensures credibility of results (26). Researcher bias was considered and reduced through the use of multi-method procedures, observation notes and the keeping of a reflective log (25). 8 questionnaires were excluded due to them being incomplete and 4 transcription codes were excluded for lacking significance.

Thematic Analysis

The coded qualitative data from both focus groups, questionnaire responses and observation notes were considered together in a Thematic Analysis. Themes are patterns identified from the coded transcriptions that highlight the key results of the data by connecting codes together into one overarching theme. Thematic analysis was suitable for identifying patterns within qualitative datasets exploring carers' ideas about mood, communication and alertness of the participants, mood and quality of life of the carers and barriers to attending sessions (25). The most significant themes are those which are supported by the most coded evidence (quotes/phrases), are stressed to be of importance from members of the focus groups and are supported

by existing theory in the literature. The resulting themes are presented in **Figures 2, 4** and **6** with the significant codes and key quotes contributing to each theme.

Statistical Analysis

A Cross Tabulation and Fishers Exact test of association was carried out using SPSS Software to analyse questionnaire responses. This is preferred to a chi square test which requires a sample of ≥30 to be powered, this research had a sample size=30 (27). It specifically looked at the association between “Change in participants’ mood” and “Change in carers’ mood”. These were selected for analysis based on aims 1 and 2 and from interpretation of the thematic analysis.

Results

Questionnaire: Section 1 – Background Information

Of the 30 questionnaire responders, 28 dementia participants were male and 2 female. The mean age group of participants was 70-79 and 2/3 of participants in Football memories sessions have been relying on care for less than 5 years. 73% of participants live in their own home and 27% receive full time care in a home.

Questionnaire: Section 2 – Participants mood

Table 2. shows that the highest significant change in participants’ mood was that 73% (95%CI 57-90%) of carers noticed an improvement in the levels of happiness following Football Memories. There were more carers reporting improvements in depressive feelings than in anxiety and agitation, with one carer describing a worsening in level of agitation in the participant. The most precise measurement is that 50% (95%CI 47-68%) of carers described improved agitation, where the confidence interval width is 21% compared to 33% in the other measurements.

Questionnaire: Section 3 – Participants Communication

Figure 1. shows that 67% of carers reported a more than normal or high level of communication during the memories session, with more carers stating that communication levels were high after the sessions compared to during.

Themes: About the participant

Figure 2. shows three themes describing the effects of football reminiscence on participants' mood, communication and alertness which support the results in **Table 2 and Figure1.** Themes 1 and 2 are the strongest themes, with four codes contributing to them. The evidence behind them is consistent, with frequent quotes reoccurring in both focus groups and in questionnaire responses. Theme 1 shows that reminiscing about football improves the participants' mood where quotes such as "*He enjoys it, he enjoys the company*" FG1Q1L10 and "*Dad is happier, more animated*" QQ3L52 show this. This is supported by **Table2**. Theme 2 is significant as it provides explanation as to why communication and enjoyment are increased in Football Memories. It's the male company triggering increased social interaction with new people who have common interests. Theme 3 surprisingly highlighted that the effects on the participant are "in the moment", this contradicts **Figure 1** where more carers noticed more significant improvements in communication levels after the memories sessions rather than during, an explanation for this could be that the carers aren't present during the therapy sessions and are basing their response off feedback from the facilitator. This theme also describes the symptoms of dementia, such as lack of communication and increased agitation, which emerge when the participants are not at Football Memories and the stimulation of their brain is reduced.

Questionnaire: Section 4 – About The Carer

Two-thirds of carers experienced a change in their mood, **Figure 3.** Shows that significantly, 63% of carers reported an increase in their happiness and 50% reported an increase in their calmness. No carer reported an increase in stress, worry, loneliness or anger, with 60% of carers reporting a decrease in stress levels and 50% reporting a decrease loneliness. **Figure 3.** specifically highlights the positive mood experienced by carers.

Table 3. shows five different aspects contributing to carer quality of life, over 50% of carers stated that they have an increase in their levels of social interaction, time to themselves and respite from Football Memories. Respite and social interaction were both increased in 53% of carers. The majority of carers experienced no change in their time with family and friends, wellbeing or sleep levels.

Themes: About the carer

From **Figure 4.** the strongest theme is Theme 4 “Company of other carers” the robustness of this theme can be demonstrated through quotes such as “ *for me, it’s being in this group*” FG2Q1L1, this quote was the first response to the question “What are the benefits of Football Memories?”, emphasising that group social interaction is just as important for carers as it is for participants. Carers enjoy this company, they laugh and feel secure learning from people like them. It is clear from Theme 6 that the carers are burdened by having to provide around the clock care, leaving them with “no quality of life”, and feeling lost. This emphasises the importance of Theme 5 “*Have a break and offload*” where Football Memories allows carers to have a break for a few hours, it is a short period of pressure relief where

they run errands and use time for themselves. *"Offloading"* to other carers provides reassurance and opportunity to *"get it off your chest"* in a short period of respite.

Questionnaire section 4: Barriers to attending sessions

Figure 5. shows that the most commonly reported factors preventing participants attending were "Hospital appointments" and "Patient illness". From **Figure 6,** Theme 8 highlights "carer availability" as the only factor hindering attendance to the sessions, only 8% of carers marked this in the questionnaire. From observations, the sessions are very well attended.

Statistical results and interpretation

From **Table 4.** it can be said that levels of depression in the participant are associated with feelings of happiness and levels of stress in the carer, where the p values for this association are 0.000 and 0.009 respectively. The level of happiness in the participant is associated with happiness in carer (p=0.028). All 3 measures of association are <0.05. Therefore all 3 null hypotheses can be rejected confirming an association between the feelings of the participant and the feelings of the carer. Particularly, in **Table 4a**, 89% of carers said they experience an increase in their happiness when depression in the participant is improved. Further to this, from **Table 4b**, more carers said their stress levels decreased when the participants depression was improved than those carers that said their stress level stayed the same. **Table 4c** shows that 77% of carers who said the participants happiness improved also said their happiness increased. An overall association between improved depression in the participant and an increase in positive feelings and a decrease in negative feelings in the carer can be made.

Discussion

The evidence presented supports the conclusion that Football Memories Reminiscence enhances mood, communication and alertness for a short period of time in the dementia patient and improves mood, quality of life and respite in the carer. The barriers to attending football reminiscence are multi-factorial and very carer dependent. This research highlighted the ongoing burden carers face and that a key barrier to attending Football Memories is the activities of the carer where, despite the social benefits of Football Memories, some need time to themselves.

In light of the first aim, participants have an elated mood and a reduction of negative feelings during Football Memories. Factors contributing to this include: enjoyment, company of other men, remembering football past times, interacting with like-minded men and sharing their knowledge of football. These findings are similar to those from a thematic analysis by Watchman(2015) (13). In a study by Chiang et al. looking at a subject group akin to that of this project, their depressive symptoms improved (12). Chiang found the sharing of personal reminiscences meaningful, supporting Theme 1 of this research where participants enjoyed bringing back fond memories and sharing football knowledge. The benefits to mood are further supported by Cotelli(2012) and Carone(2016), who did a qualitative investigation, where an emerging theme was “Enjoyment and Anticipation”, like Theme 1 above (16) (6). One participant experienced a worsening of agitation, this was also observed in the latter half of the observation of FG2 and in Watchmans’ 2015 pilot study (13). It was concluded that 90minute sessions could be too long to remain focussed. Literature suggests that sundowning, “*confusion or agitation in dementia patients in the afternoon*” could explain this, independent of the memories session (28). The main effects on communication and alertness are positive, reminiscence therapy creates

“in the moment” improvements to social interaction, especially in a group of males (11). This is due to enhanced stimulation of the brain to think about discussing football in a group. Harmer and Orrell(2008) said that activities involving past interests are more meaningful so enhance thought in dementia patients (29). O’Philbin and Woods concluded similar effects in their 2018 systematic review, where group reminiscence enhanced communication and interaction immediately after therapy (10). Woods however disagrees with Theme 3 “effects are in the moment” and showed that effects can last for weeks/months after the therapy, although small (10). Schofield(2015) showed that the positive effects on mood and communication are short-lived, which supports the themes here (11). It’s known that through creating a supportive social environment, communication and social relationships in people with dementia improves, Football Memories is an example of this (30) (31).

The second aim explored the impacts of Football Memories on the carer, specifically their mood, respite and quality of life. It is clear that carers face a chronic caregiver burden demonstrated through quotes such as ”we have no quality of life”. The themes draw out the complexities of caring for someone with dementia which echo through an increasing amount of dementia literature, including that of Watchman and Tolson(2015), Schofield(2010) and others (4) (32) (33). Further studies have shown that the neuropsychiatric symptoms of dementia, such as delusions and agitation are the most distressing to carers, precipitating further pressures (32) (33). These stresses in informal carers can lead to inadequate levels of care and worsened outcomes for the dementia sufferer. This research shows that the caregiver burden is temporarily relieved during Football Memories where carers mood and quality of life were improved. The reliability and validity of this result alone on explaining

effects on the general caregiver population is weak, but is strengthened and explained by Themes 4 and 5 where the simple act of chatting with others has many social benefits for carers, including accessing support and reducing stress. It therefore isnt surprising that Football Memories provides a 90minute period of respite and subsequent improvement in carer quality of life. Jonas-Simpson et al.(2006) stated that the act of being listened to is a fundamental aspect of quality of life, here the carers described “getting it off your chest” when they talk to other carers, “offloading” their burdens (34). This proved how valuable conversation with people in a similar situation is in maintaining the mood and quality of life of this population of informal care givers (35). Short periods of carer respite could become a secondary focus for Football Memories reminiscence therapy protocols, where more frequent sessions could enhance quality of life and functionality of carers allowing them to care for the dementia sufferer more effectively (36). This could delay or minimise hospital admissions for dementia patients, improving their wellbeing by providing effective care at home.

The themes are credible, transferable and valid; also emerging in theory and current literature, however in ensuring this, the density of the data collected was high and could only be analysed in shallow detail due to time limitations of this research. The qualitative approach introduced researcher subjectivity in the resulting themes, where meaning behind themes could be lost or interpreted differently by others. Despite this strengths include multi-modal data collection and use of thematic and statistical analyses which increased the meaning, reliability and significance of the results.

A lot of the novel reminiscence research has been on life story/individual reminiscence therapy and guidelines are veering toward encouraging individualised

therapy (8). As described in this project, group reminiscence therapy has many benefits. Football Memories Scotland should, going forward, be considered further in the national dementia strategy 2017-2020 (8). It is currently addressed within the strategy as a way of “encouraging dementia friendly communities”. There is evidence in this project and other studies that Football Memories could do more for managing and treating dementia beyond community involvement. It is still in the early stages of development and more thorough neuroscience and outcome based quantitative research is required to solidify these findings with scientific theory. Further studies should look at group reminiscence therapy in greater detail, particularly the impacts on carers and use this research as a starting point in explaining the effects of Football Memories and how it can be implemented throughout practice as a non-pharmacological approach to dementia therapy.

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Tables and Figures

Table 1 Abbreviations used in location tagging of codes identified in the transcriptions of qualitative data sources.

1st Item	Data Piece	Focus Group 1 Focus Group 2 Questionnaire Observation of 1st memories session Observation of 2nd memories session	FG1 FG2 Q OB1 OB2
2nd Item	Question number	Question 1 Question 2 Etc.	Q1 Q2
3rd Item	Line within the transcript the evidence can be found	Line 1 Line 23 Etc.	L1 L23
Example:	FG1 Q1 L1 word or phrase was located within the transcription of Focus Group 1 in the section answering question 1 and within the 1st line of the transcript text.		

Table 2. The proportion of carers who said **feelings in the participant** improved as a result of football memories sessions

Feeling	**Mean Proportion of carers who said "improved"**	**Standard Deviation**	**95% Confidence Interval of mean**	**Significance**
Happiness	73%	45%	57%-90%	Significant
Depression	63%	49%	47%-80%	Significant
Anxiety	57%	50%	40%-73%	Significant
Agitation	50% (3% said worsened)	57%	47%-68%	Significant
Apathy	57%	50%	40%-73%	Significant

Figure 1. Pie chart showing change in communication levels during (a.) and immediately after (b.) Football Memories session:

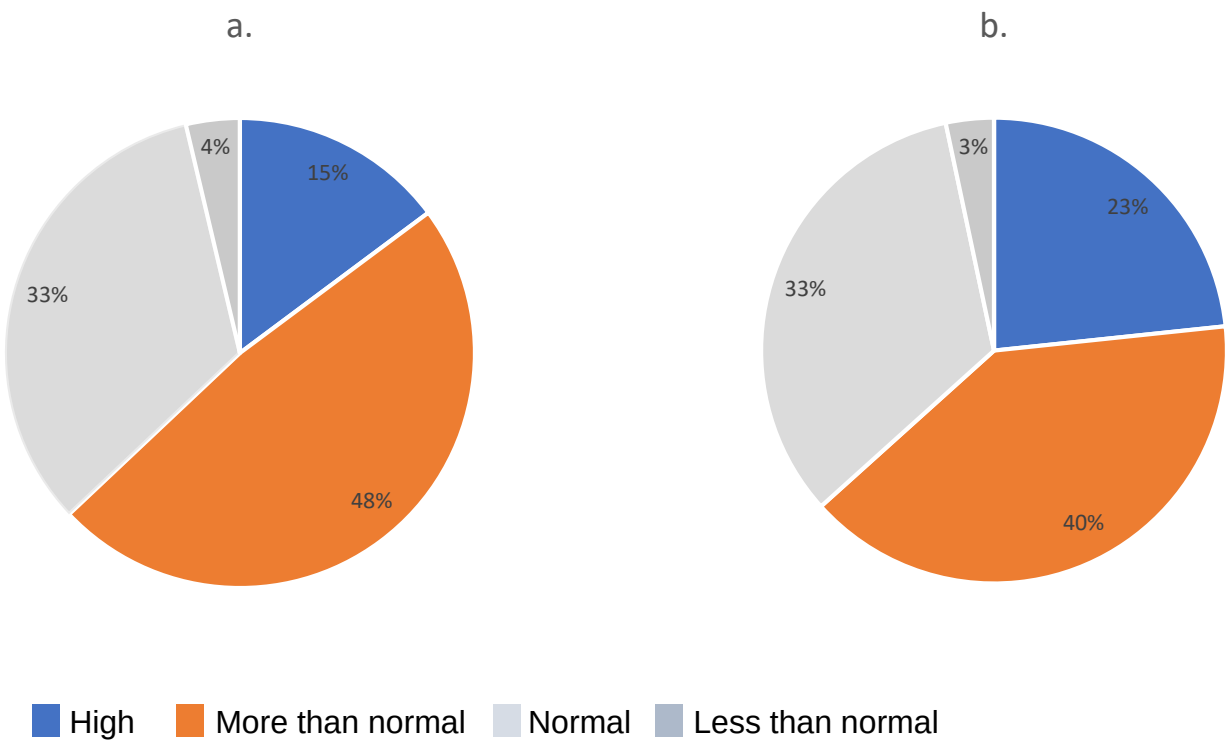

Figure 2: Flow diagram showing the emerging themes on the effects of Football Memories **on the participant** from numbered codes and one phrase from the transcription contributing to that code.

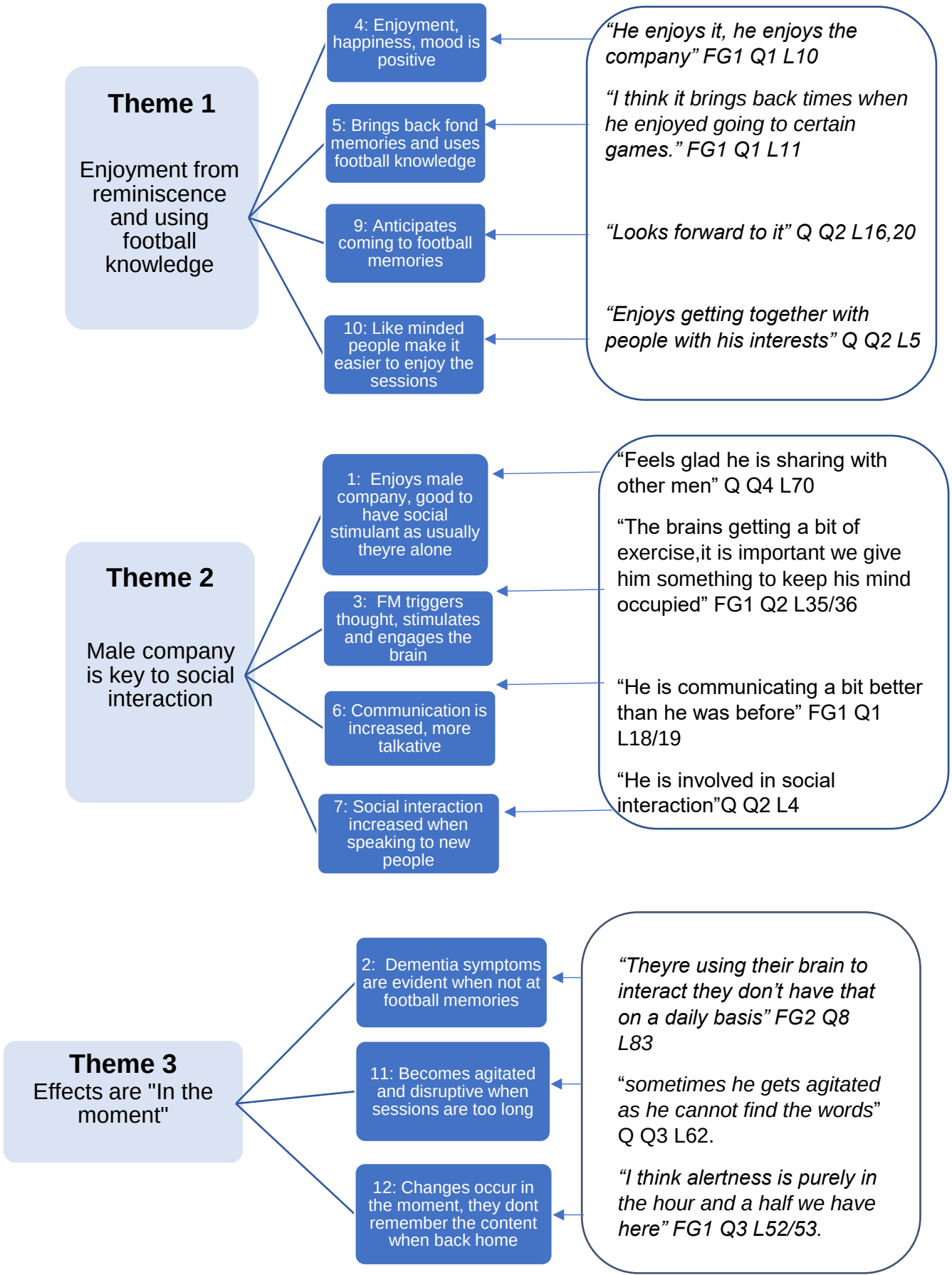

Figure 3. Self-reported change in feelings of 30 carers contributing to carers mood

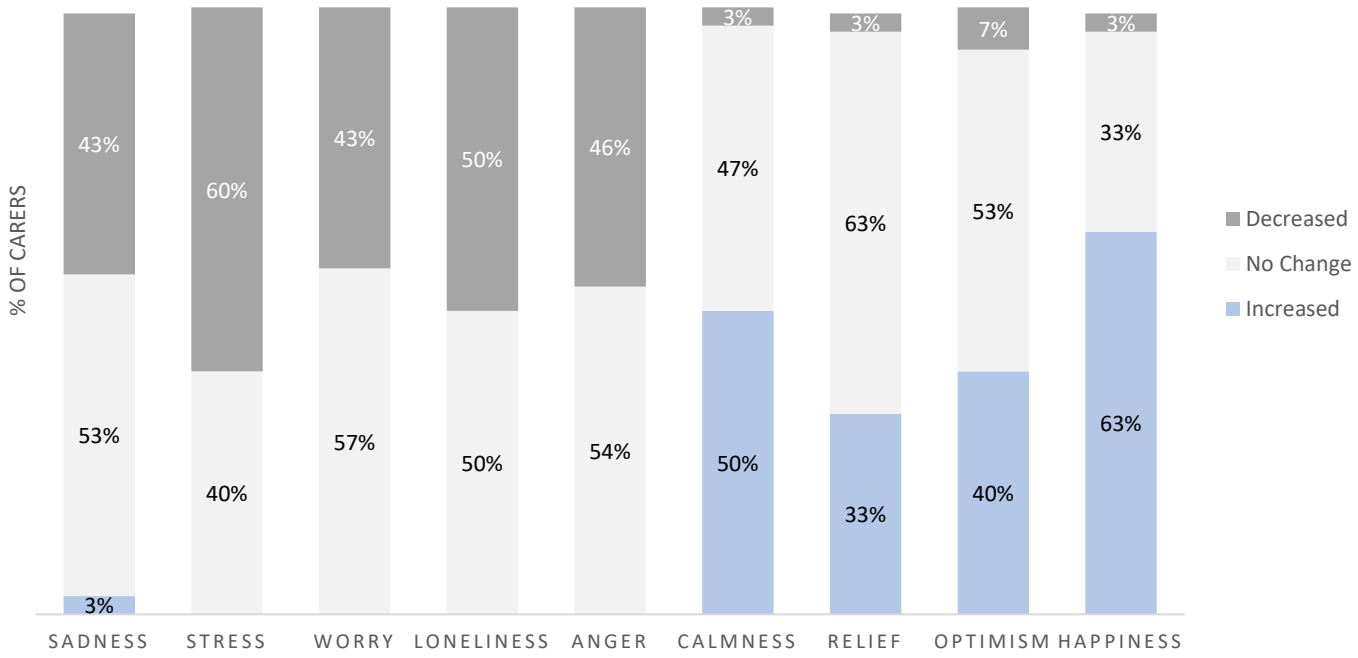

Table 3. Carer change in factors influencing quality of life

	Factors contributing to carer quality of life						
		Social Interaction	Time to yourself	Respite	Sleep	Time with others	Wellbeing
% of carers reporting a change	**Increased**	53%	50%	53%	7%	33%	47%
	No change	47%	43%	47%	90%	63%	50%
	Decreased	0%	7%	0%	3%	3%	3%

Figure 4: Flow diagram showing themes 4-6 on the effects of Football Memories on **the carer** from numbered codes and one phrase from the transcription contributing to that code.

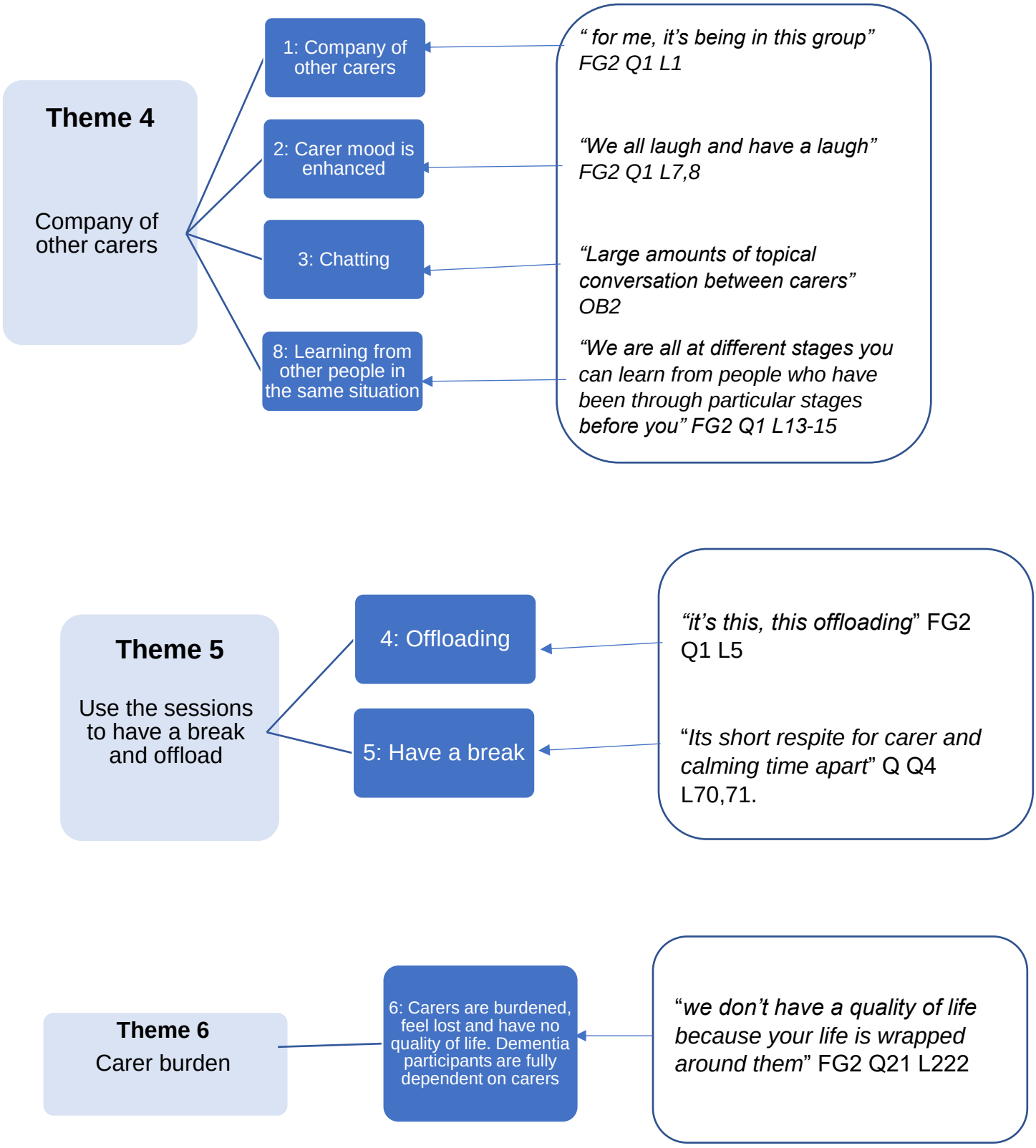

Figure 5 Factors preventing participants and their carers attending sessions

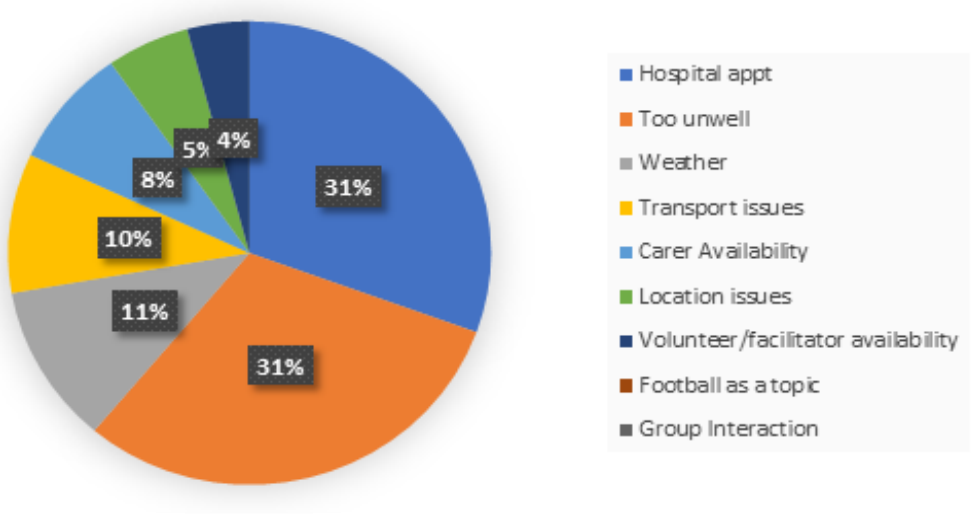

Figure 6. Theme 8 with respective codes describing carers' views on the barriers preventing participants attending Football Memories:

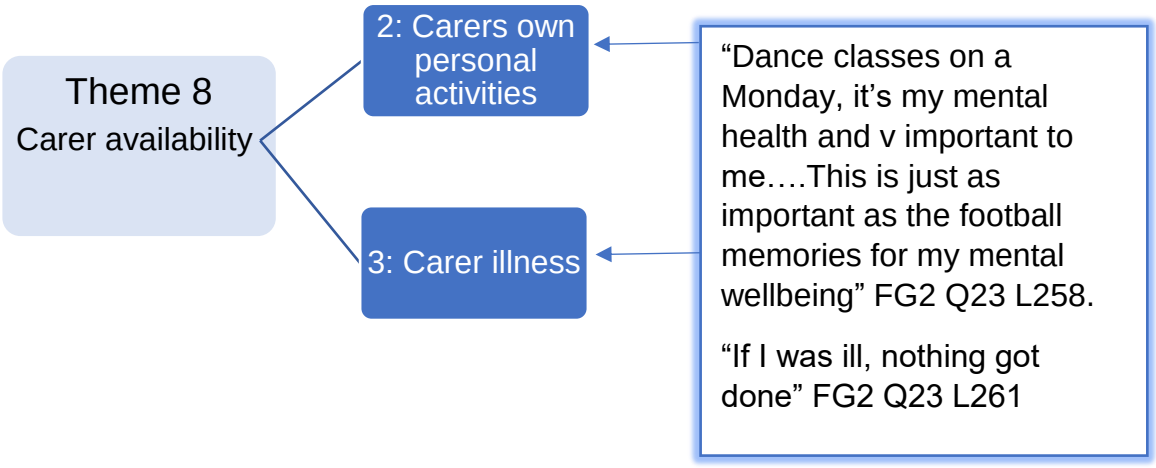

Table 4. Cross Tabulation and fishers exact test of association between mood in the carer and mood in the participant

a) **Depression** in participant and **Happiness** in carer.

		Happiness in Carer			Fishers Exact sig. (2-sided)
		No Change	Increased	Total	.000
Depression in participant	No Change	9	2	11	
	Improved	2	17	19	
	Total	11	19	30	

b) Depression in participant and **Stress** in carer.

		Stress in Carer			Fishers Exact sig. (2-sided)
		No Change	Increased	Total	.009
Depression in participant	No Change	3	8	11	
	Improved	15	4	19	
	Total	18	12	30	

c) Happiness in participant and **Happiness** in carer.

		Happiness in Carer			Fishers Exact sig. (2-sided)
		No Change	Increased	Total	.028
Happiness in participant	No Change	6	2	8	
	Improved	5	17	22	
	Total	11	19	30	