

EXPLORING CARER EXPERIENCES OF A STRUCTURED CARER WELLBEING INTERVENTION

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OUTLINE

- Experience of caregiving in psychosis
- Rationale for the development of the Carer Wellbeing Intervention
- Outline of the intervention
- Service context
- Evaluation of the intervention
 - Quantitative evaluation
 - Qualitative research project
- A carer's perspective
- Challenges

ROLE OF A CARER

- Emotional support
- Practical support – e.g. money, housing
- Recognising and responding to relapse
- Treatment adherence



EXPERIENCE OF CAREGIVING IN PSYCHOSIS

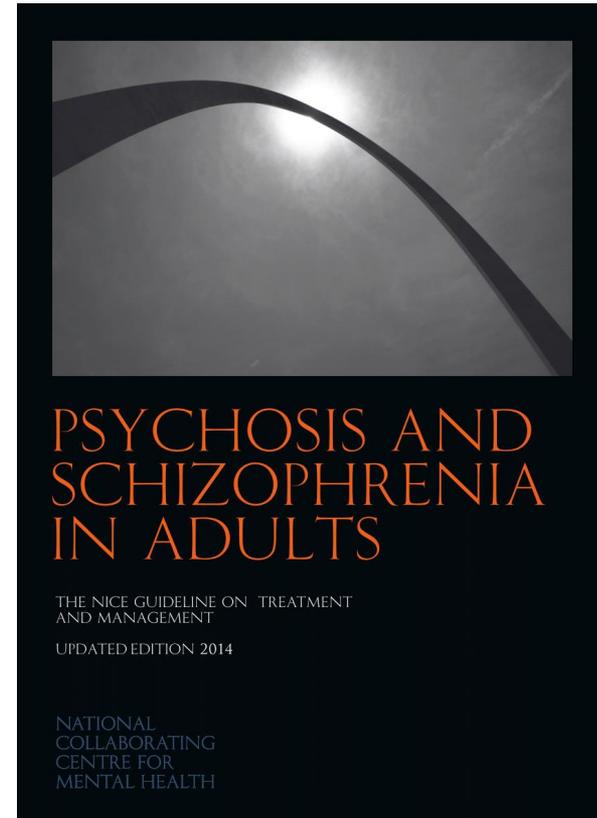
- High levels of burden (Magliano et al., 2003; Patel et al., 2004)
- High levels of burnout (Onwumere et al., 2015; Angermeyer et al., 2006)
- 30-40% report clinical levels of depression (Raune & Kuipers, 2004)
- High levels of loss and grief (Patterson et al., 2005)
- 30-40% report PTSD symptoms (Kingston et al., 2015; Loughland et al., 2009)
- Social isolation (Hayes et al., 2015)
- More than 50% experience violence and aggression (Onwumere et al., 2014)
- Stigma and shame associated with mental health difficulties which can reduce the social networks of carers (Magliano et al., 2005; Gutierrez-Maldonado, Caqueo-Urizar & Kavanagh, 2005)

EXPERIENCES WITH SERVICES

- Feeling invisible to services (Sin, Moone & Wellman, 2005)
- Askey et al., (2009):
 - *“There is no consistency who's in the team as sometimes you can see a different doctor every time. There needs to be more consistency. Once you're in the system you're too scared to drop out in case things get worse. X was discharged several times and this made things worse. Teams should hold on to service users for a longer time.”*
 - *“Sometimes the professionals don't listen and understand what's actually happening with X. They should listen to what carers are saying more. It makes me feel frustrated.”*

NICE RECOMMENDATIONS

- NICE guideline: Psychosis and schizophrenia in adults: prevention and management (2014)
- 1.1.5.1 Offer carers of people with psychosis or schizophrenia an assessment (provided by mental health services) of their own needs and discuss with them their strengths and views. Develop a care plan to address any identified needs, give a copy to the carer and their GP and ensure it is reviewed annually. **[new 2014]**



NICE RECOMMENDATIONS

- 1.5.3 Give carers written and verbal information in an accessible format about:
 - diagnosis and management of psychosis and schizophrenia
 - positive outcomes and recovery
 - types of support for carers
 - role of teams and services
 - getting help in a crisis
- 1.1.5.7 When providing information, offer the carer support if necessary. **[new 2014]**
 - Offer a carer-focused education and support programme, which may be part of a family intervention for psychosis and schizophrenia, as early as possible to all carers. The intervention should:
 - be available as needed
 - have a positive message about recovery

TRANSLATING NICE GUIDANCE

- Family Intervention (FI) presents an opportunity for carers to be offered support
- However:
 - Not all families/family members will engage in FI
 - Family members have their own needs, which may not be able to be addressed in FI
 - There is evidence to suggest that offering a stepped care model of intervention to carers can be useful (Onwumere, Grice & Kuipers, 2016)
 - FI can be challenging to set up which can delay working with carers

PILOT STUDY



Research Article

A pilot investigation of a brief, needs-led caregiver focused intervention in psychosis

Sarah Roddy, Juliana Onwumere, Elizabeth Kuipers

- A pilot study based in SLaM (Roddy, Onwumere & Kuipers, 2015) indicated that a time-limited, structured intervention for carers:
 - Reduced distress
 - Reduced depressive symptoms
 - Achieved high levels of acceptability and satisfaction

NELFT PILOT

- NELFT developed and piloted a structured carer wellbeing intervention for EI carers currently in contact with the Trust's Home Treatment Team (HTT)
- Learning from this project :
 - Carer-focused interventions are acceptable and well received
 - There is a need to support carers and a lack of resources to provide this care
 - Stepped care interventions can improve access to support
- These findings were used to create a business case to the CCGs when they were considering the investment required for the Referral to Treatment Target (RTT)

CARER WELLBEING INTERVENTION

- 6-8 individual weekly sessions with the team's Assistant Psychologist
 - Assessment of caring experience
 - Psychosis psychoeducation
 - Carer wellbeing
 - Signposting to other services
 - Crisis planning and carer support planning
- A written protocol is followed and supervision is used to support its implementation

CARER WELLBEING INTERVENTION

- Assessment of caregiving experience
 - Assessment of current difficulties & goal development
 - Formal carer's assessment
 - Outcome measures
- Psychosis psychoeducation
 - Working together through a booklet about Psychosis
 - Using this as a platform to discuss their own experiences and feelings

CARER WELLBEING INTERVENTION

- Carer wellbeing
 - Consideration of how the family member looks after themselves
 - Reconnecting with activities and interests which they may not be doing due to their caring role
- Signposting to other services
 - Linking carers up with local organisations
 - Making referrals to IAPT
- Crisis planning and carer support planning
 - Relapse prevention planning

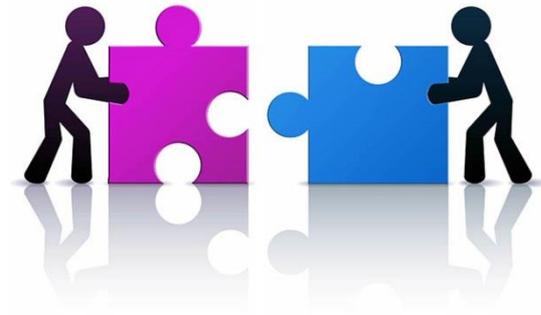


FI AND CARER WELLBEING COMPARISON

Family Intervention	Carer Wellbeing
Person experiencing psychosis is included	Conducted with just the family member in a one-to-one session
Two therapists deliver the intervention – Psychologists or other clinicians who have been trained in FI	Team's Assistant Psychologist delivers the intervention
At least 10 sessions offered	A maximum of 8 session offered
Typically fortnightly meetings but there is flexibility around this	Typically weekly meetings but is flexibility around this
Sessions usually occur in the home but there is flexibility this	Sessions can occur either in the family home or in the team base

KEY PRINCIPLES

- No referral system for the Carer Wellbeing Intervention – it is offered to everyone, including those with multiple family members in a caring role
- Offered in addition to the option of FI
- Flexibility in delivering the intervention – session frequency and location is matched to the needs of each carer



SUPPORTING THE DELIVERY OF CARER WELLBEING INTERVENTION

- Supervision:
 - Two hours per week of individual supervision
 - Two hours per month of group supervision (APs only)
 - Group supervision for supervisors
- Training:
 - Three day block of induction training
 - Ongoing bi-monthly training and skill development
- In-role support:
 - Observations and joint working with Clinical Psychologists



BEYOND INDIVIDUAL WORK

- Being a “voice” for the carers – presenting different narratives within the team
- Supporting carers in crisis e.g. attending ward rounds/medical reviews
- Practical support e.g. benefits applications
- Coordinating the carers groups

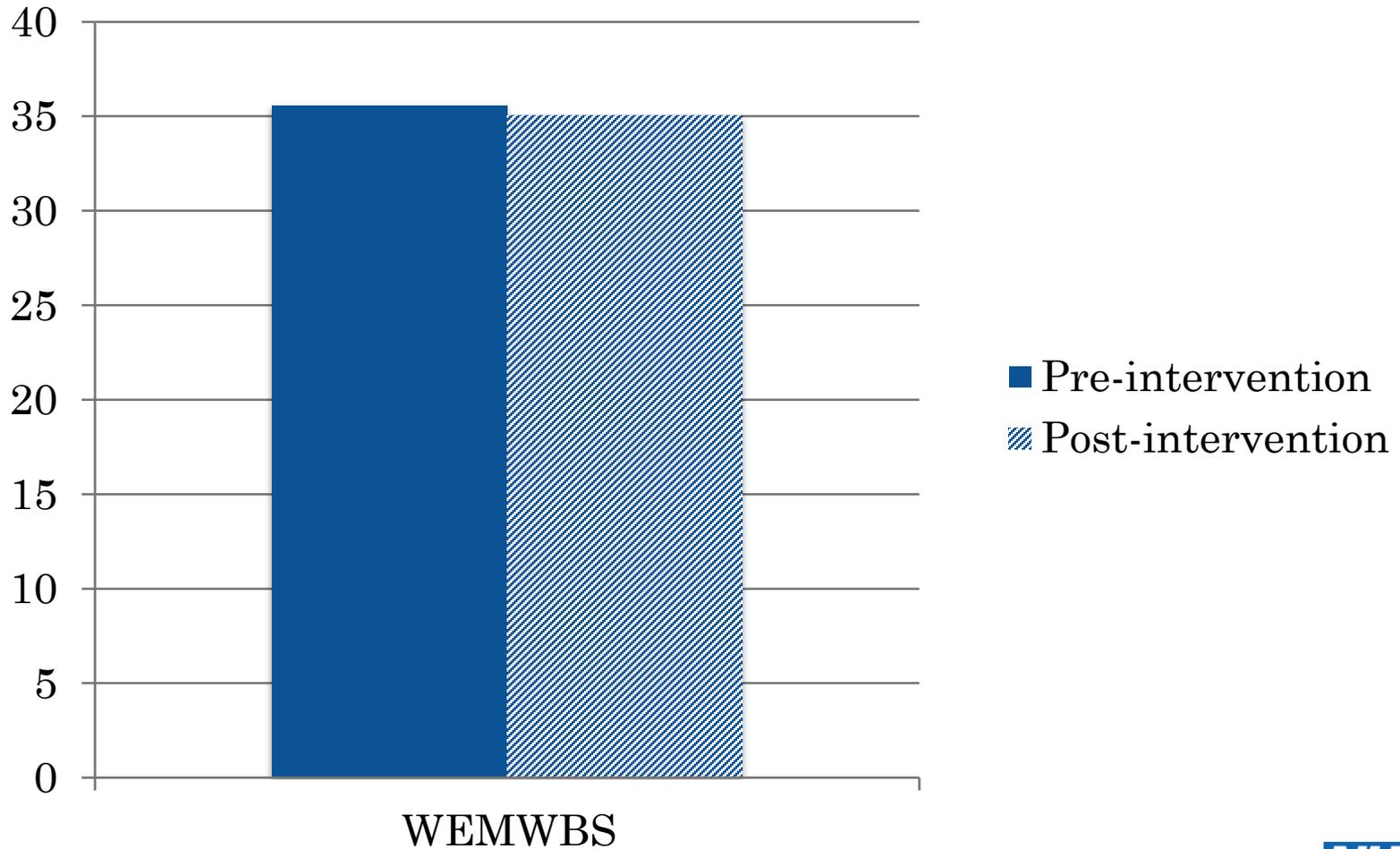


EVALUATION OF THE CARER WELLBEING INTERVENTION

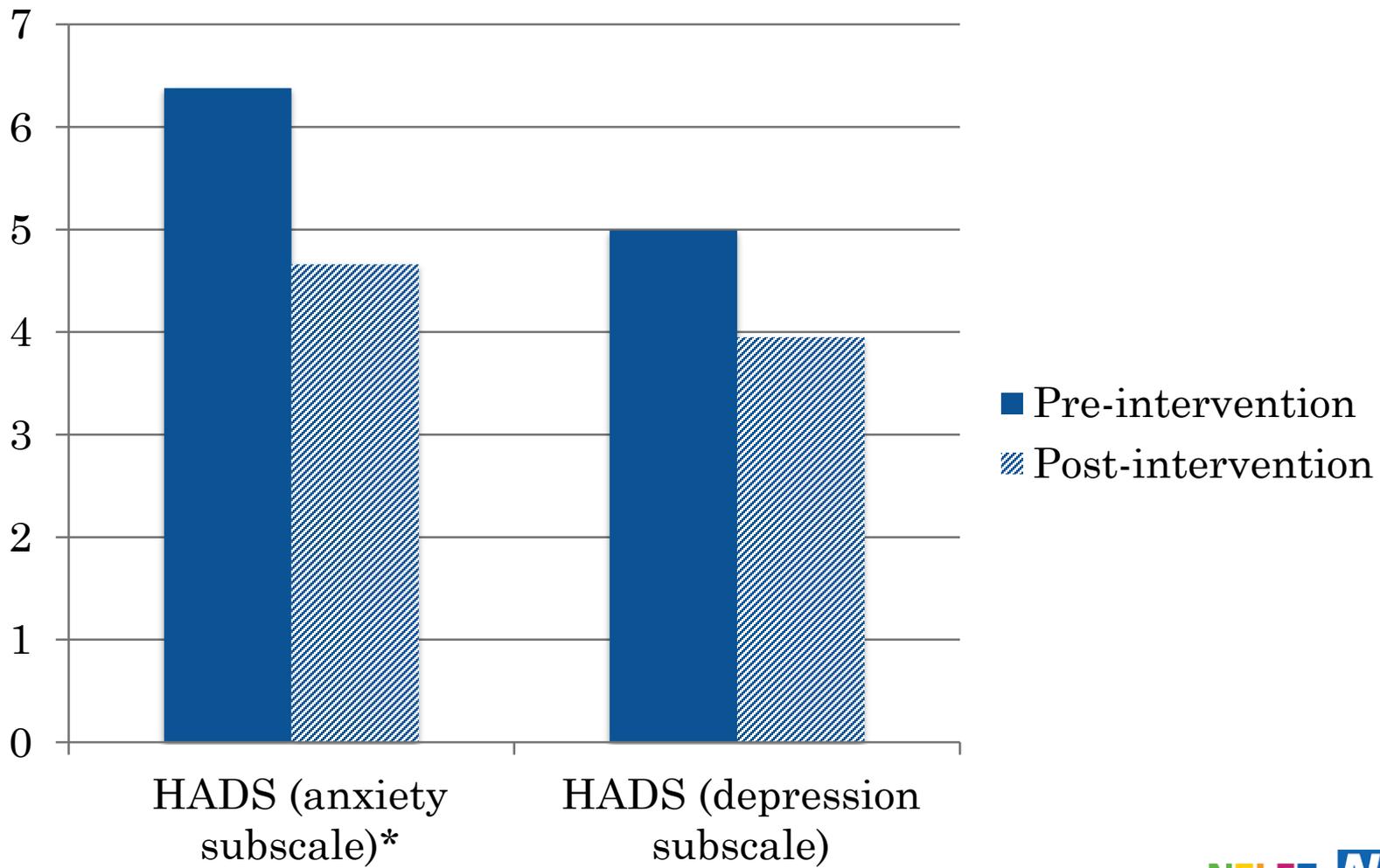
- 94 carers completed pre and post-intervention outcome measures
- These included:
 - Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS)
 - Experience of Caregiving Inventory (ECI)
 - Hospital Anxiety and Depression Scale (HADS)
 - Session feedback form (post-intervention only)



QUANTITATIVE ANALYSIS - WELLBEING

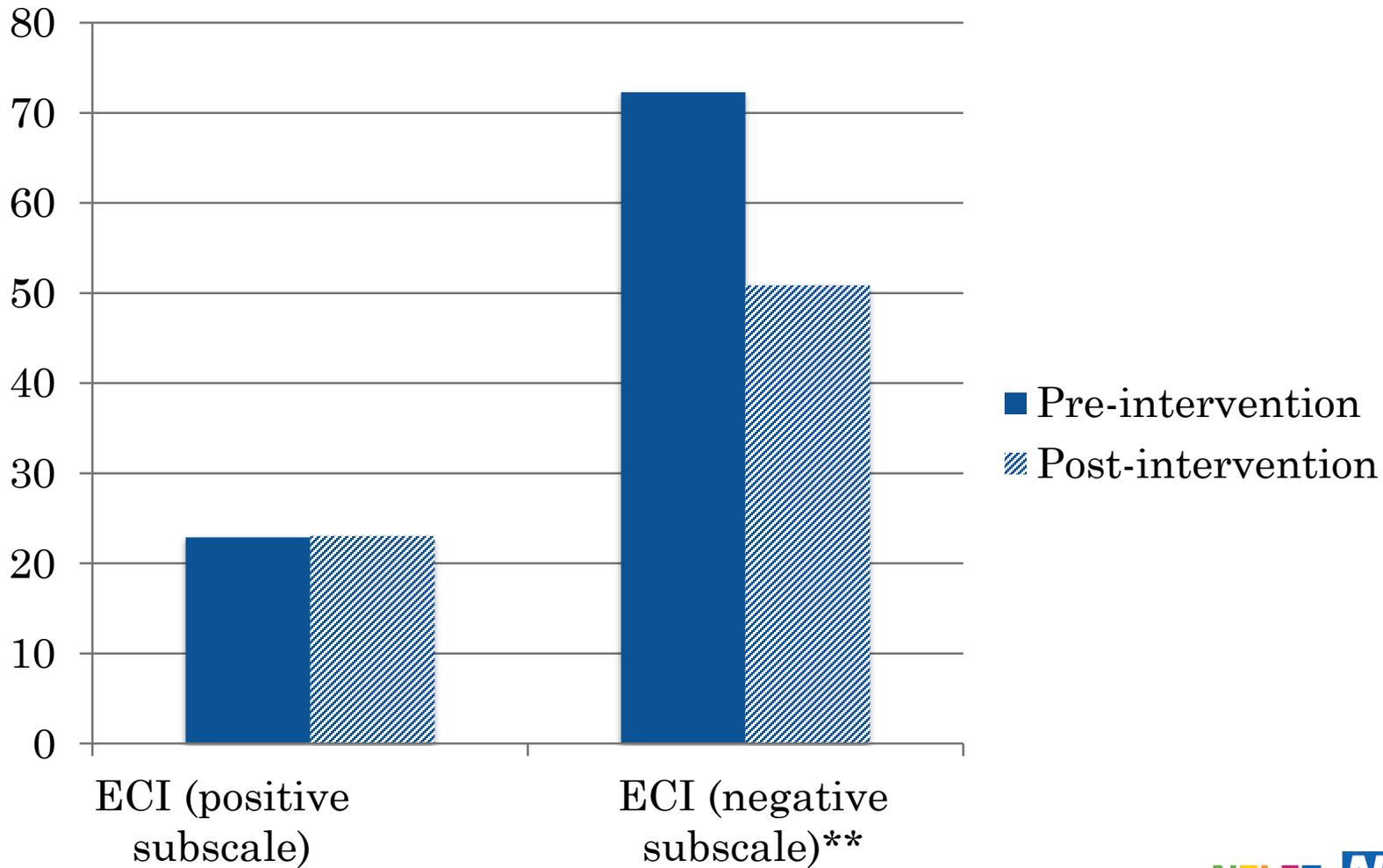


QUANTITATIVE ANALYSIS - MOOD



*significant to $p < 0.05$

QUANTITATIVE ANALYSIS – EXPERIENCE OF CAREGIVING

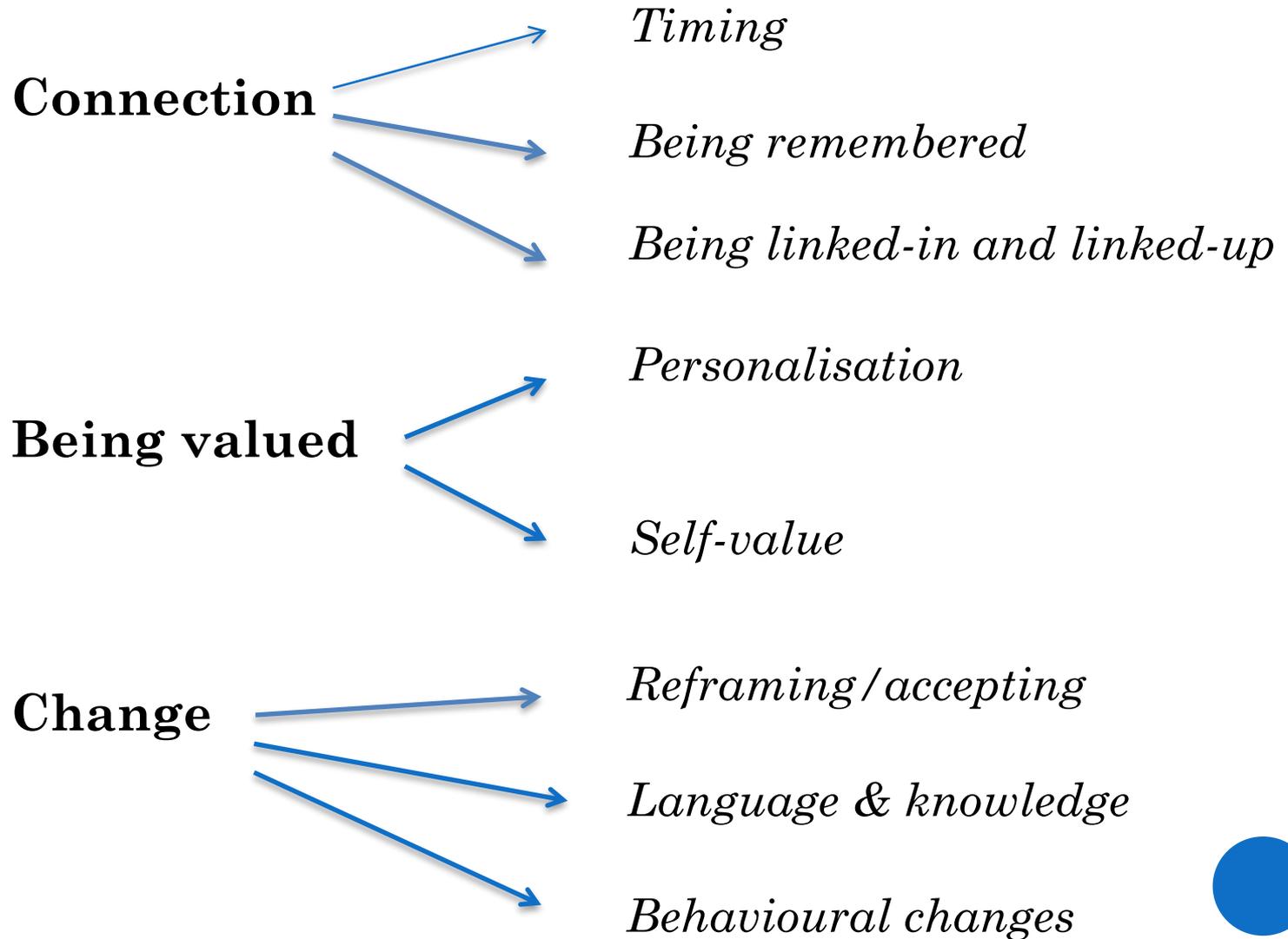


** significant to $p < 0.001$

QUALITATIVE EVALUATION

- Semi-structured interviews were conducted with 9 carers
- Aims: To learn about carer experiences of the carer wellbeing intervention offered within the service
 - What worked well
 - What could be different
 - How easy/difficult it was to access the sessions
 - Expectations and reality
 - Changes they had experienced

THEMES IDENTIFIED



CONNECTION

- Sessions helped carers to feel more involved with the team. Within this, the timing of when they were offered the intervention was considered important in having this connection

Timing

“...Maybe I sort of thought I’m not sure what else I could learn, but I was wrong...and I could have missed out it. I think maybe there was something about the timing of when it was offered, like it could have been better a bit earlier”

CONNECTION

Being remembered

“I think you just feel like everyone is busy and they won't need me getting in contact and things like that. It was so nice to be contacted, to know they thought I'd be okay. It definitely helped me manage and to keep going with the positive changes I had made before”

Linked-in and Linked-up

“...it was also so nice to know the team more and to know I didn't need to worry as I knew who the people would be there to make sure my brother was doing well”

“...knowing you're not on your own in this...that's a big part of wellbeing”

BEING VALUED

- Carers thought that sessions gave them a new sense of feeling valued. The level of personalisation for clients was reported as reassuring. This was often talked about as being important to their wellbeing

Personalisation

“...I read a lot on the internet as well but she [Assistant Psychologist] just put it in a different perspective, our perspective. She explained certain things that I didn’t understand. If I had a question she would help me understand it”

BEING VALUED

Self-value

“You know there’s something that made me then spend a little bit of time on myself during each day instead of worrying about everyone all the time...I didn’t do that before”

“ ...It even just made me actually think about my own wellbeing. You know thinking that I have to try and take it easier; try to do things to help my stress...”

CHANGES

- Carers identified change that they attributed to the sessions. These spanned language, behaviours and their understanding of past events

Reframing/accepting

“...she [client] would be abusive to me. She was very hurtful and it was all part of it. I did not know that before and so it was upsetting...then I knew it was part of her illness so then I just used to...give her the comfort she needs”

CHANGES

Language and knowledge

“...before we didn’t know who to call if he had a setback or a psychotic episode...I mean we didn’t even know what to call it, how to say it. Once you have that language to say that on the phone they then know what you are talking about, yeah they know what questions to ask you. It was really not knowing how to describe what was happening, or what was going on and the sessions helped that”

“...Yes, cause as I say, I didn’t really know what the full extent...could mean...like it was also learning that hearing something can be a hallucination. I just didn’t know. It was putting words to things and having the terminology”



CHANGES

Behaviour change

“Well like it’s definitely had an impact. Even my daughter said to me you’re really different...my daughter found I was always interrupting my son, her and everyone. She said that I was so much calmer that I listen more to what my son says, before I speak. She noticed a massive difference in me.”

“Yes. I don’t argue anymore, I can just think I will walk away, before I would have argued my point, argued that was he was saying was wrong. That’s helped our relationship, I think.”

A CARER'S PERSPECTIVE – SUSAN'S EXPERIENCE

CHALLENGES

- Further flexibility in intervention delivery
- Prioritising wellbeing within the sessions
- Multi-disciplinary team's understanding of the intervention
- Feeding back carer perspectives to the team



QUESTIONS



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