Evidence for Working with Families: Incorporating a Vigorous Model of Family Psychoeducation into Models of Care

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Thanks: Jenny Burger, Dr Margaret Leggatt

NSW Rehabilitation Psychiatry Network Meeting

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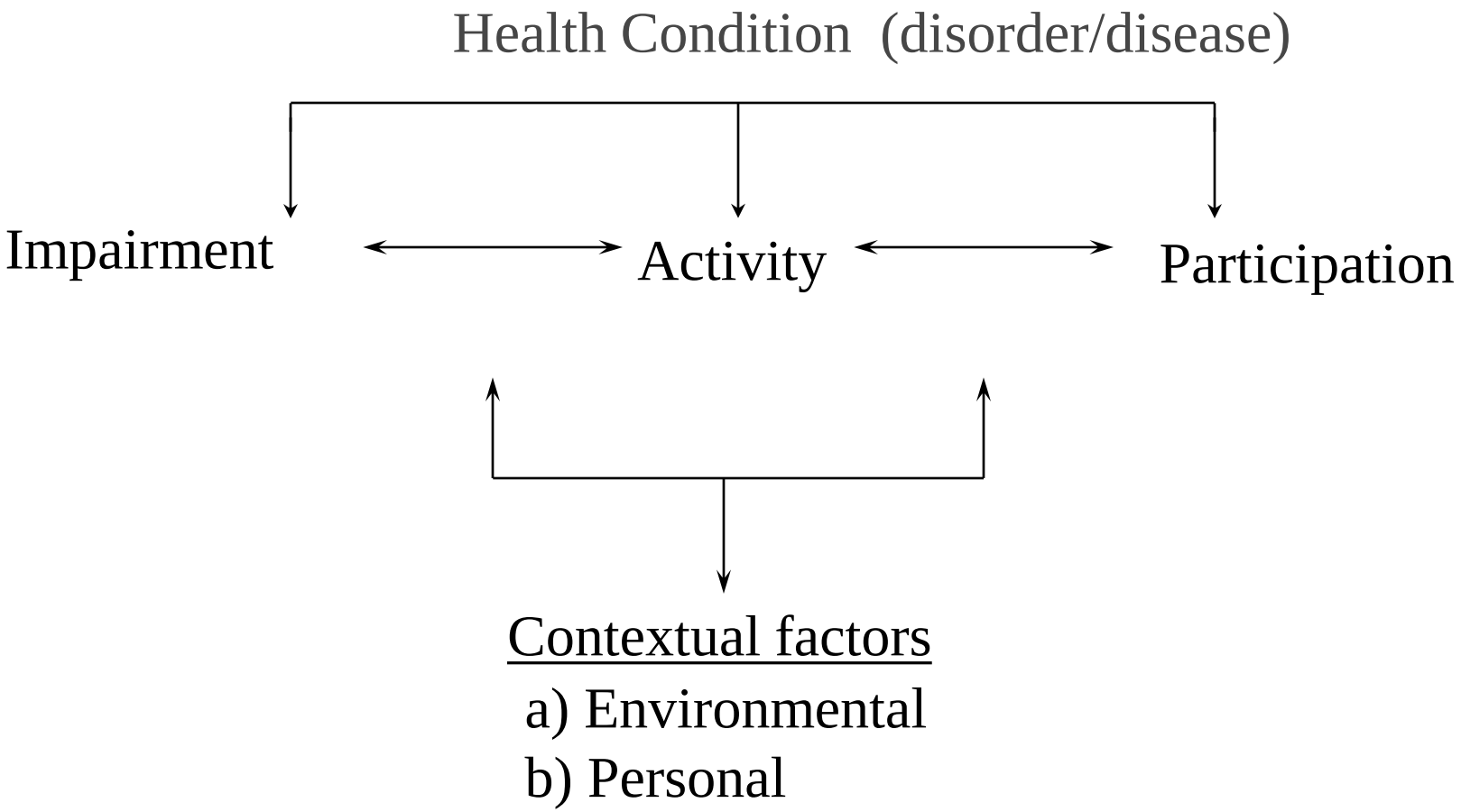
WHO International Classification of Functioning

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Extent and significance of family caring

- 225 421 co-resident carers of adults with mental illness in Australia according to 2012 Survey of Disability, Ageing and Carers (1.0% of the population)
  - Estimated 103 813 additional mental health carers not living with their care recipient (*Diminic et al, 2018*)
- Most people with psychotic disorders have frequent face-to-face contact with family members in the previous year:
  - 56.5% almost daily, 17.1% at least once a week (*Morgan et al., 2012*)
- If involved in treatment through appropriate interventions and programs, family carers can positively contribute to consumer recovery
  - Consumer viewpoints consistently emphasize diverse supports, including families, are helpful for sustaining jobs, dealing with work issues, and facilitating job seeking (*Fossey & Harvey, 2010*)

Epidemiology and Psychiatric Sciences (2017), **26**, 265–275.
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ORIGINAL ARTICLE

A longitudinal population-based study of carers of people with psychosis

A. W. C. Poon[1*], C. Harvey[2], A. Mackinnon[3] and L. Joubert[4]

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ORIGINAL ARTICLE

WILEY Health and Social Care in the community

Perceived needs of carers of people with psychosis: An Australian longitudinal population-based study of caregivers of people with psychotic disorders

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Community Ment Health J (2015) 51:591–597
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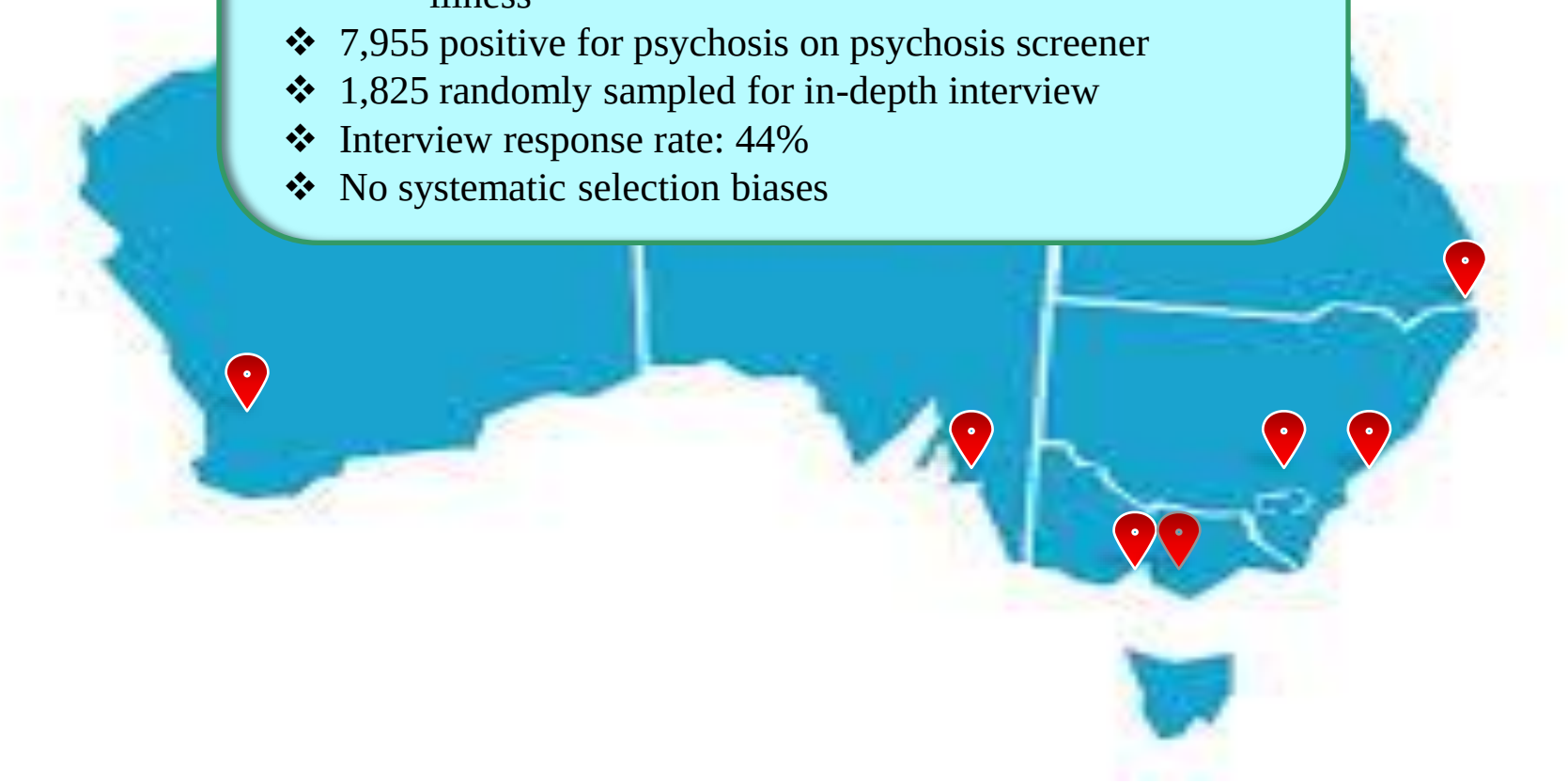
BRIEF COMMUNICATION

Quality of Life and Social Isolation Among Caregivers of Adults with Schizophrenia: Policy and Outcomes

Laura Hayes · Graeme Hawthorne · John Farhall · Brendan O'Hanlon · Carol Harvey

2010 Australian National Survey of Psychosis

- Adults aged 18-64 years
- 7 catchment sites in 5 states
- Coverage: ~ 10% of Australian population aged 18-64
- Treatment services:
  - Public specialised mental health services
  - NGOs funded to support people with mental illness
- 7,955 positive for psychosis on psychosis screener
- 1,825 randomly sampled for in-depth interview
- Interview response rate: 44%
- No systematic selection biases



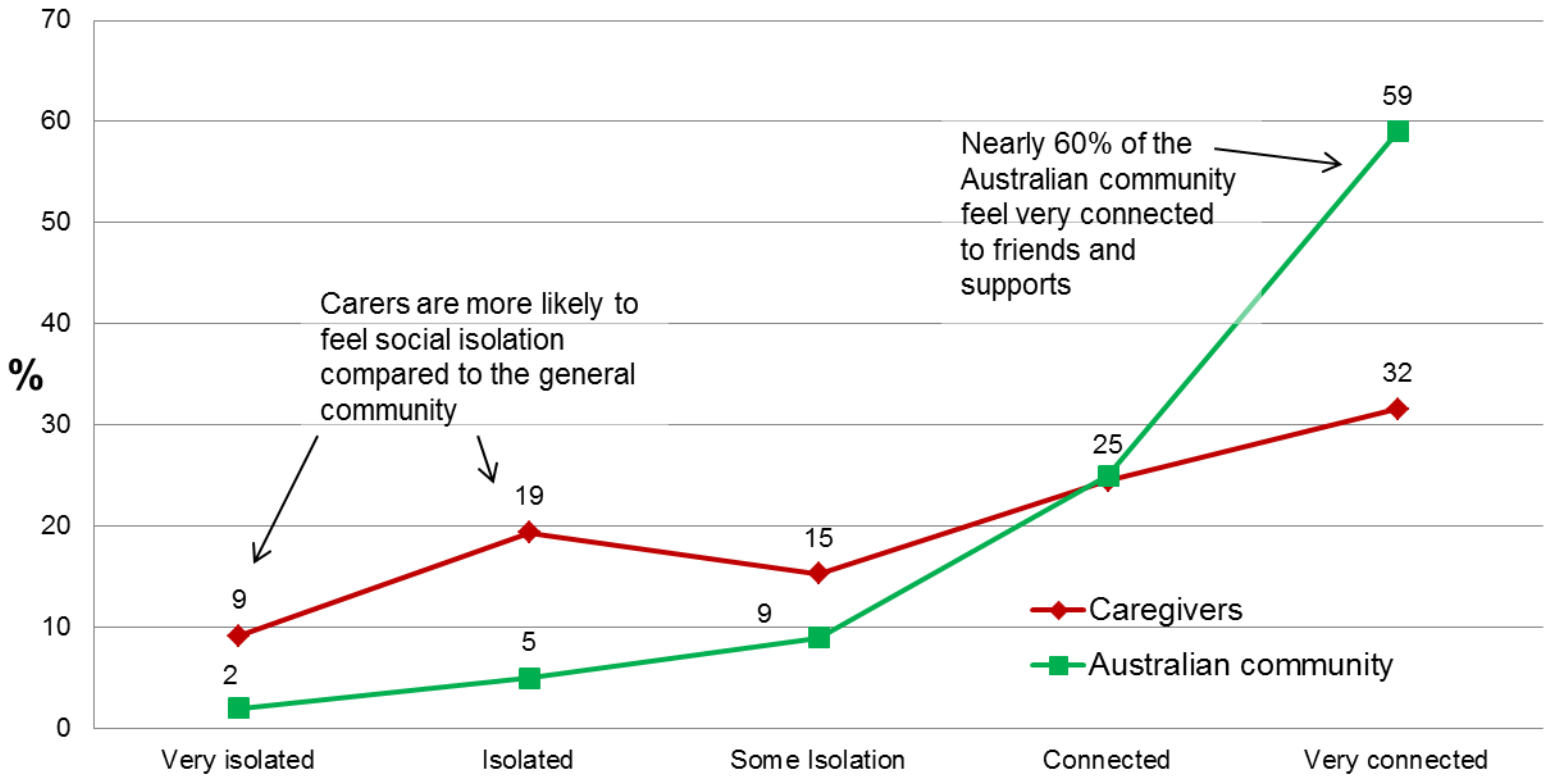
Family Situations – What are They?

- National survey - parallel study of carers:
  - 98 carers – mostly relatives - providing support to people with psychotic illnesses participating in the national survey in Victoria
  - Families had been caring, on average, for 7 years
  - Carers were more isolated and had a poorer quality of life than the rest of the population
  - Two in five carers experienced probable depression or anxiety

(*Poon, Harvey, Mackinnon & Joubert, 2017*)

Family Carers are Often More Socially Isolated than the General Community

(*Hayes, Hawthorne, Farhall, O'Hanlon & Harvey, 2015*)



Are Family Needs Adequately Addressed in Routine Service Delivery?

- No significant changes for all carers' health and wellbeing variables after one year, except carers had a poorer perception of their quality of life (physical health)
- Lack of improvement suggests carers' needs are largely unaddressed by routine mental health service provision
- Carers were **more** distressed, isolated and experienced more grief if they **perceived their consumer relative to have difficulties with functioning (according to LSP20)**

(*Poon, Harvey, Mackinnon & Joubert, 2017*)

Are Family Needs Adequately Addressed in Routine Service Delivery?

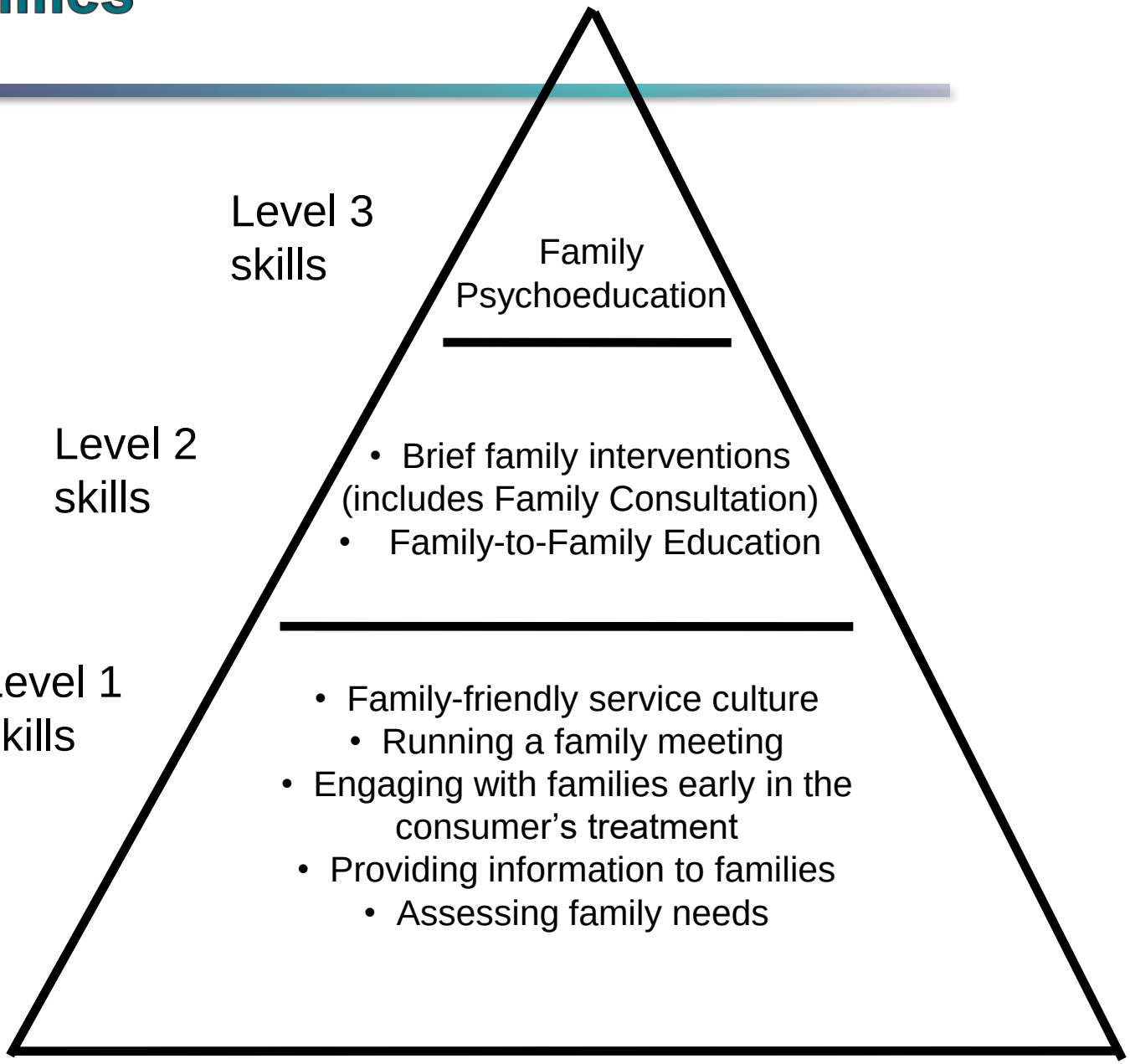
- Semi-structured interviews (baseline, one year later) to assess changes in carers' perceived needs (Carers' and Users' Expectations of Services – Carer version)
- Minimal improvement in carers' perceived needs over time (only improvements: help with information about care workers & help in dealing with risk or safety issues)
- Amongst the five themes – thematic analysis:
  - Carers needed diverse types of biopsychosocial support
  - Needed wellbeing and independence interventions for their consumer relative

(*Poon, Joubert & Harvey, 2018*)

In Summary….

- Extent and nature of caring
  - Three in every five consumers living with psychosis have frequent contact with their family
  - Mutually supportive and rewarding, but also can have a negative impact on carer health and wellbeing
- Family needs are poorly met within routine service delivery
- Families recognise the need for rehabilitation interventions for the consumer and would likely benefit themselves from the consumer receiving rehabilitation
- Addressing family needs can benefit both the family and the consumer

Stepped Approach to Including and Involving Families



Family Psychoeducation: Recapping the Evidence

- Family Psychoeducation – various forms – includes Multi-Family Groups and Behavioural Family Therapy
- Information, support and skills (re-)training [=universally applicable skills] for all family members, including the consumer
- Consumers living with schizophrenia → any mental health condition in which relapses are likely
- Address the link between intra-family stress, how this may undermine communication and problem-solving, and increased likelihood of relapse of the consumer

Family Psychoeducation: Recapping the Evidence

- Since 1970s, >50 RCTs
- Reduced relapse & admission rates – by 20-50%
- For every 7 families treated, one relapse of a relative living with schizophrenia is prevented during one year (i.e. Number Needed to Treat 7, CI 6-8)
- Similar effect sizes to prescription of anti-psychotic medications in the treatment of schizophrenia
- Other psychosocial outcomes:
  - Better social connections
  - Improved employment

(*Harvey & O'Hanlon, 2013; McFarlane et al, 2012; Pharoah et al, 2010; Pfammatter et al, 2006; Pilling et al, 2002; Pitschel-Walz et al, 2001*)

Family Psychoeducation: Recapping the Evidence

- And family psychoeducation helps reduce impact of caregiving on family members
  - Less psychological distress
  - Reduced caregiver burden
  - Improved intra-familial relationships and family functioning

(*Cuijpers, 1999; Barbato et al, 2000; (Martin-Carrasco et al, 2016; Perlick et al, 2018)*

State of the evidence as reflected in guidelines

- Family psychoeducation is effective and should be offered routinely in the comprehensive care of schizophrenia (NHMRC level 1 evidence, EBR)

  (RANZCP Clinical Practice Guidelines for the management of schizophrenia and related disorders, 2016)

- Offer family intervention to all families of people with psychosis or schizophrenia who live with or are in close contact with the service user (strong recommendation, quality of evidence = good practice point)

  (Psychosis and schizophrenia in adults: prevention and management. NICE, 2014)

- Continue to offer people with complex psychosis individual CBT and family intervention as recommended by the NICE guideline on psychosis and schizophrenia in adults (strong recommendation, with very low to moderate quality of evidence)

  (Rehabilitation for adults with complex psychosis NICE, 2020)

A systematic review of randomised controlled trials of interventions reporting outcomes for relatives of people with psychosis: Lobban et al, 2013

Table 4
Intervention content and number of interventions effective on any outcome (n=47 studies).

	Number of studies	
Components	Effective	Ineffective
Psychoeducation	28	15
Managing problem behaviours	24	12
Setting realistic expectations	20	7
Problem solving training	21	10
Communication training	17	7
Stress management for relatives	17	6
Challenging unhelpful beliefs	13	5
Relapse prevention	21	9
Emotional support	11	22
Maintaining social networks	16	5
Vocational rehabilitation	7	1

Community-based social interventions for people with SMI: systematic review & narrative synthesis

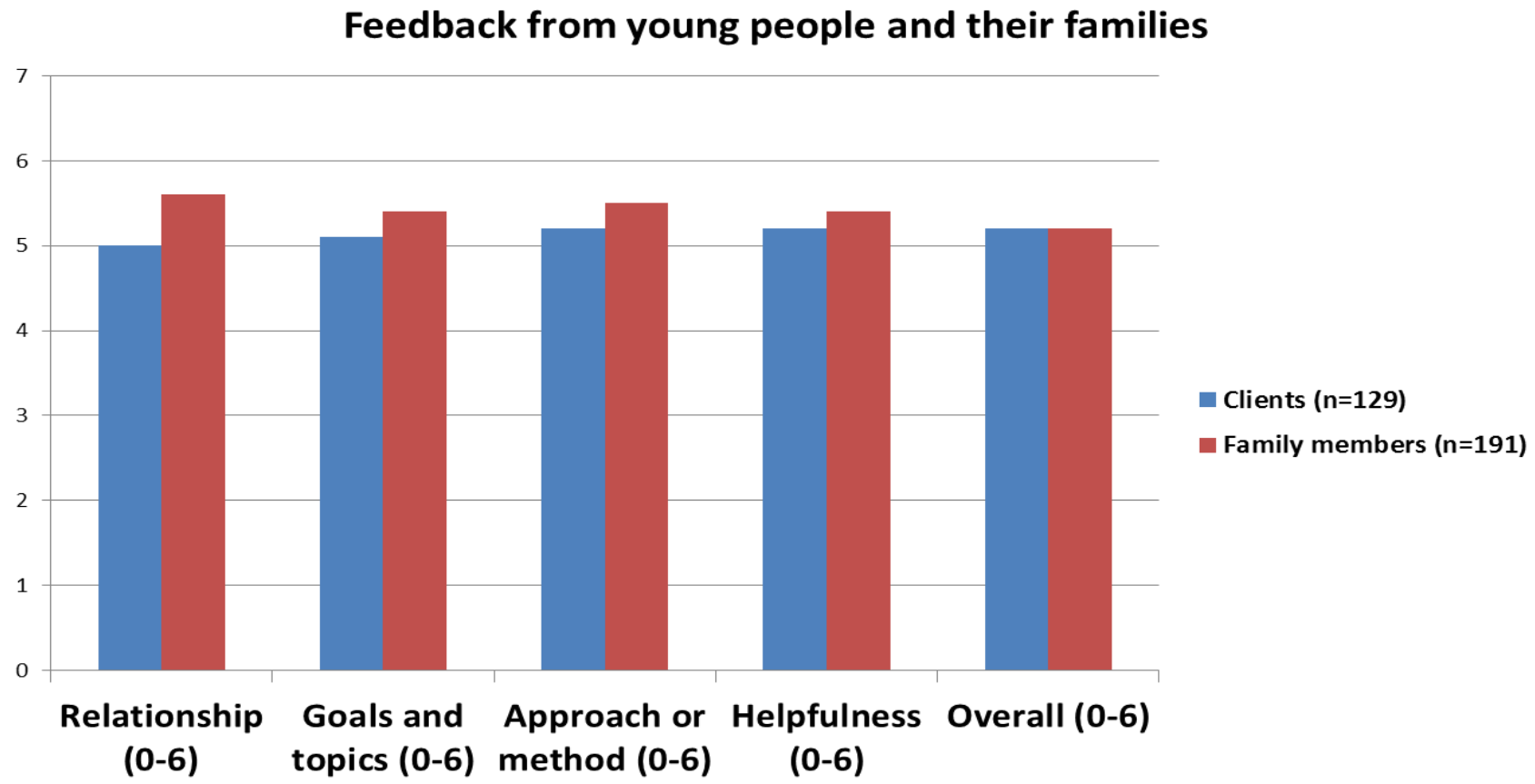
- 11 papers assessing family interventions: 4 quantitative studies (3 RCTs); 1 qualitative; and 6 mixed methods
- Varied interventions: all included psychoeducational elements; a number also included cognitive behavioral strategies
  - Carers showed significantly reduced caregiver burden compared with the control group in three RCTs of high to moderate quality
  - Relatives of people with psychosis or bipolar disorder used an online family intervention – both intervention and control groups showed improved well-being and experience of support
  - Several qualitative studies - potential improvements in social inclusion for all participants - service users and family members
  - Trend for peer workers as co-facilitators of family interventions
- = family interventions facilitate better social connections and relationships, improved functioning and reduced carer burden

(*Killaspy, Harvey et al, World Psychiatry, 2022)*

Single Session Family Consultation (*Poon et al, 2019*)

- Evaluated introduction of SSFC in 4 headspace centres over 1 year
- Very acceptable: 200 invitations to young people and their families to participate, 39.5% were declined
- Workers reported increased confidence and familiarity with working with families at follow up
- Improved organisational support e.g. supervision and mentoring; support from co-workers to include families; clear policies and protocols
- National roll-out
  - SSFC rolled out to at least 70 headspace centres

Satisfaction ratings for young people and their families



More examples of successful programs in Australia

- Family-to-Family Education Groups **(***Stephens et al., 2011***)**
  - Pre-post evaluation - family participants' worrying, tension, urging and distress were significantly lower following the program
  - Carers of people with a psychotic disorder experienced significantly greater reductions in worrying than did other carers
- Multi-family groups (*Bradley et al, 2006*)
  - English- and Vietnamese-speaking families living with schizophrenia
  - Reduced relapse and improved vocational outcomes

Improved Symptomatic, Functional and Quality of Life Outcomes among Consumers in the MHCSS Family Psychoeducation Program

Outcomes for consumers (n= 29) after participating in BFT in BFST Mind program (means, SDs, and statistically significant changes in pre-post scores)

			Pre		Post				
Scales	Sub-Scales	n	Mean	SD	Mean	SD	t	df	p
FS		28	13.9	6.3	15.4	5.3	1.43	27	0.16
WHOQOL-bref	Physical	26	45.9	18.1	50.1	17.4	1.41	25	0.17
	Psychological	26	40.1	19.0	49.2	22.0	2.20	25	**0.04***
	Social Relationship	26	52.2	21.3	51.3	20.8	0.21	25	0.84
	Environment	26	56.7	19.1	67.5	15.8	3.09	25	**0.00***
BASIS-32	**TOTAL**	22	1.5	0.8	1.1	0.8	2.58	21	**0.02***
FAD-GFS		29	2.4	0.6	2.1	0.5	2.40	28	**0.02***
DAI		23	3.7	4.5	3.8	4.7	-0.18	22	0.86

*** Significant at the 0.05 level**

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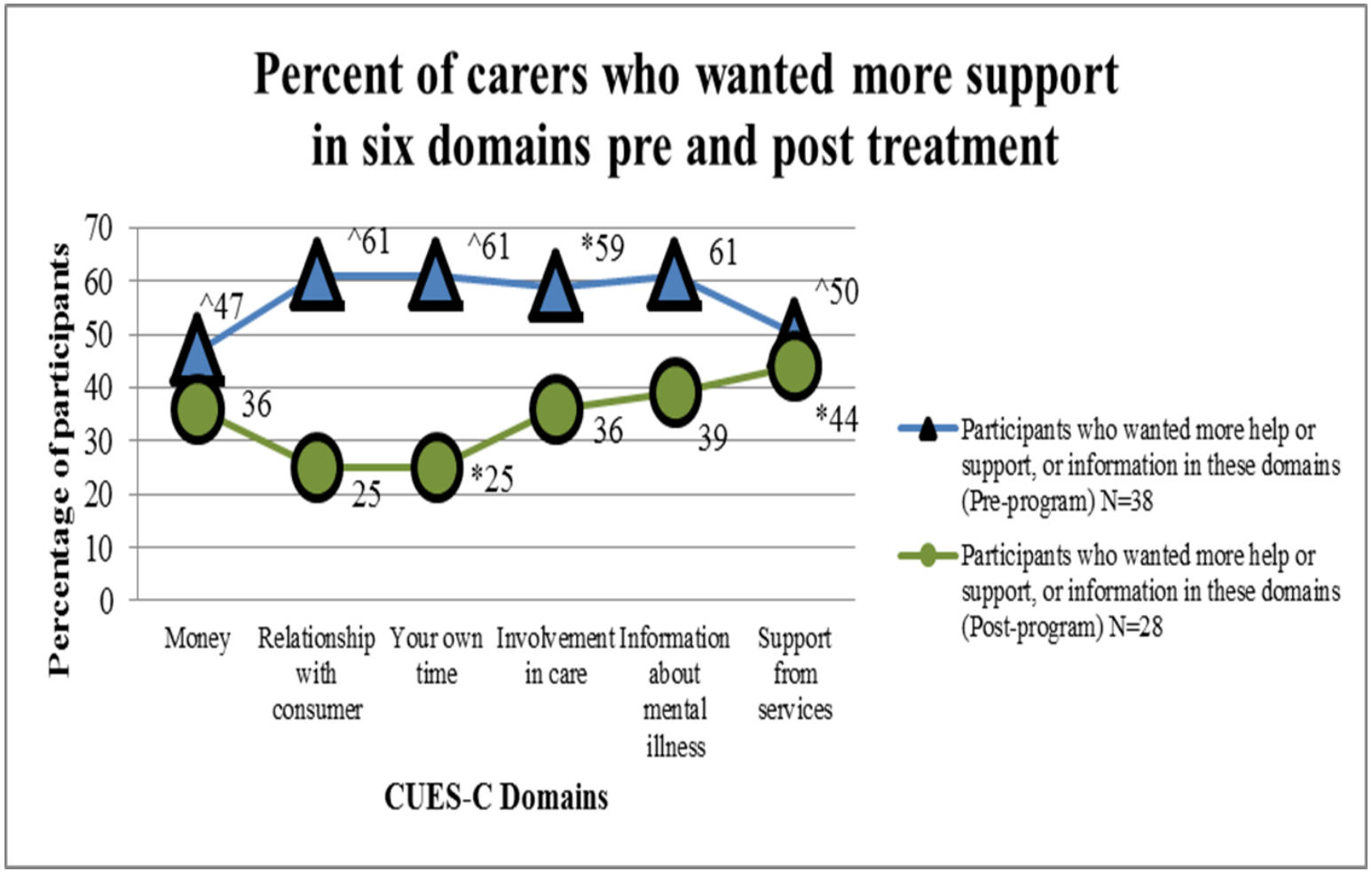
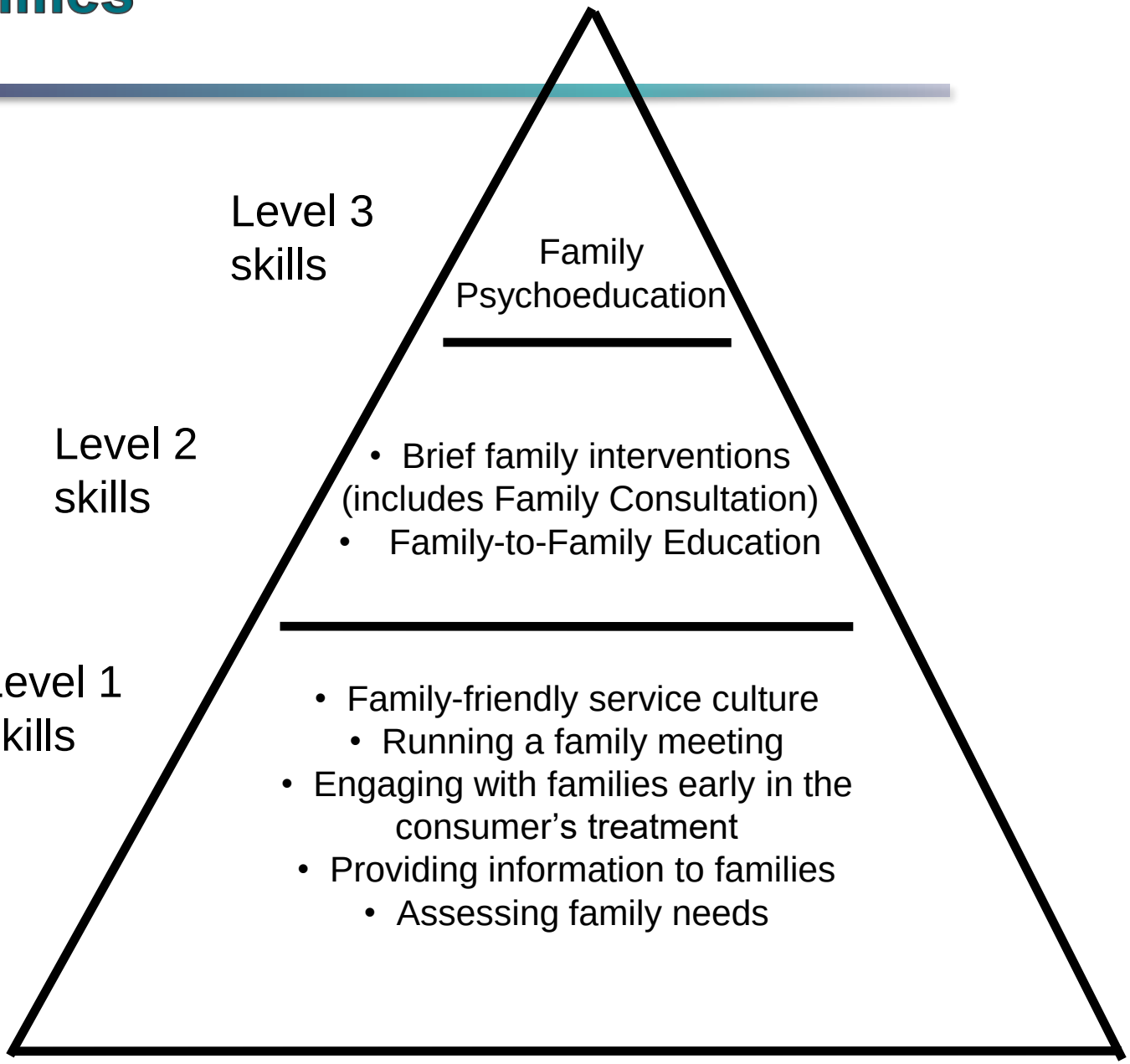
Reduced Needs among Carers in an MHCSS Family Psychoeducation Program (Coker et al, 2016)



Some Characteristics of Mental Health Services that Effectively Implement Family Inclusion and Psychoeducation

- Clinicians are trained, AND staffing and service systems are reformed
- Early engagement of families is essential – by all clinicians
- Service delivery is re-designed so there is a stepped or tiered approach to including families
- At levels 2 and 3, the work is more skilled and takes more time, which requires a small specialist subgroup of clinicians who:
  - Have sufficient time to do this work separate from other duties
  - Have enough opportunity to practise the intervention so as to gain confidence and skill
  - Are provided with regular supervision and mentoring
  - Have regular opportunities for co-working with an experienced therapist

Stepped Approach to Including and Involving Families



Some Strategies for Bridging the Evidence-practice Gap

- Staff/team
  - Improve staff knowledge, skills AND attitudes
  - Tailored training for managers and team leaders
  - Supervision, co-working, dedicated time, communities of practice
  - Peer workers
- Systems of care
  - Sub-teams of different staff, each trained in one intervention
  - Consider suitable ‘delivery vehicle’?
  - Needs assessments, KPIs and monitoring, position descriptions
- Intervention
  - Basic practices e.g. need family involvement to enable family psychoeducation

RANZCP information-sharing with families/whanau/carers

- Professional Practice Guidelines on Information sharing with families/whanau/carers
- How to have the conversation: Information sharing with families/whanau/carers

Conclusions

- Families:
  - Important as social context for most consumers who could benefit from rehabilitation
  - Are potential partners in rehabilitation
  - Have their own needs due to impact of SMI on them in their caring role which should be specifically and intentionally addressed – includes effective rehabilitation for the consumer
  - Addressing family needs and (at least some of) the consumer's needs for rehabilitation can both be achieved through family involvement, for which there is robust evidence
  - There is evidence for successful implementation of family programs in Australia, but a failure of systematic implementation and scaling up of the evidence
  - There are useful strategies for successful implementation

Thank you

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