The experiences of people affected by dementia: Voices from an ethnically diverse sample in the Eden District of South Africa

Reflections of a white female researcher

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Programme

Background

Demographic info of participants

Brief findings

Social work in South Africa

Intersections between roles of researcher and social worker

Reflections

Background

PWD diagnosed every **3 seconds** (ADI, 2021)

55 Million people worldwide are living with dementia of which 60% in LMICs (WHO, 2021)

94% PWD in LMICs are cared for at home (Prince *et al*., 2015)

Research question

What is it like to live with or care for someone with dementia?

Official classification

- Black African (9 groups)
- Coloured*
- Indian / Asian
- White
- 11 Official languages

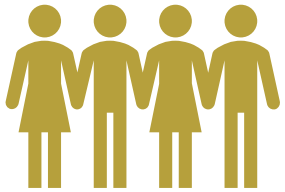
Demographics

- 3 Ethnic groups (Coloured, Black African and White)
- 18 PWD
- 30 Care partners (CPs)
- 103 qualitative interviews
- Transcribed verbatim, analysed using Nvivo and manual coding.

*Some PWD were also CPs

Aspect	Description	PWD	Care partners
Gender	Male	7	9*
	Female	11	26*
Ethnic group	Coloured	8	18
	Black African	3	4
	White	7	11
	Indian/Asian	0	1
Age (mean)	Male	81 (75-87)	62 (43-87)
	Female	75 (62-89)	59 (34-84)

Socioeconomic backgrounds



Low household income

Prior engagement with social services

Middle and high household income

No prior engagement with social services

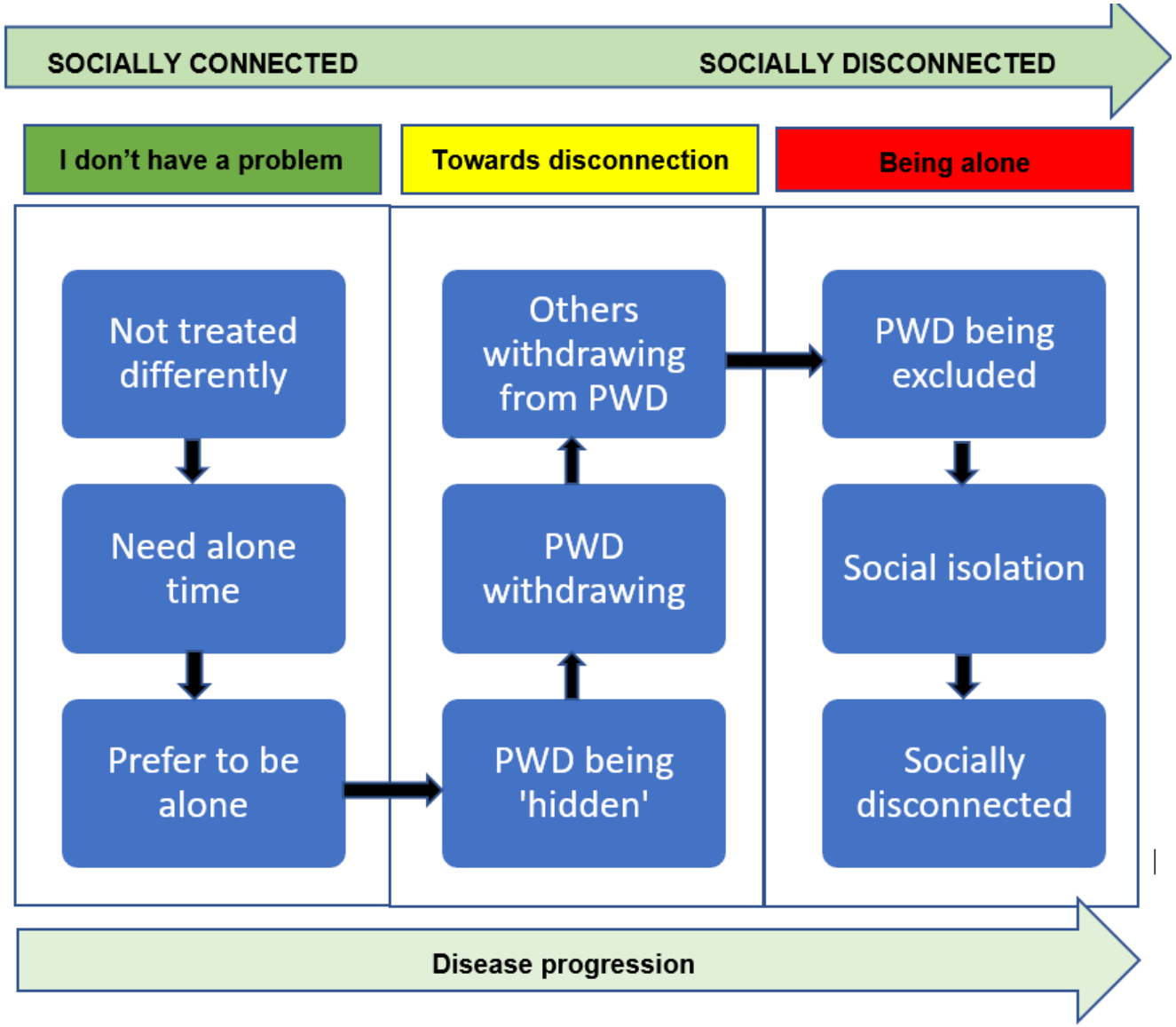
Research strategy

ASPECT	DESCRIPTION
Research design	Informed Constructivist Grounded Theory
Setting	Three municipal areas of Eden District in Western Cape province, South Africa (George, Oudtshoorn and Mossel Bay).
Recruitment	Local memory clinic and research centre, newspapers, radio talks, and word of mouth.
Sampling	Purposive and snowball sampling followed by theoretical sampling.
Participants	Persons with dementia aged 60 and older. Care partners that supported the PWDs.

ASPECT	DESCRIPTION
Data collection	
a) Screening instruments	• Community Screening Instrument for Dementia (short version) (CSI'D)
a) Demographic questionnaire	• Demographic information of participants
a) Languages	• Afrikaans and English
a) Repeated interviews	• Participant homes or memory clinic offices. • Pre-interview plus up to four interviews per participant. • Audio-recorded and transcribed.
Data analysis and transcription	• Transcribed by researcher. • Analysis assisted by NVivo.
Ethics	University of Edinburgh (UoE) REC (UK) Human Science Research Council (HSRC) REC (SA) Department of Social Development (DSD) REC (SA)

Findings

Continuum between feeling socially connected and socially disconnected



Four factors

Predominant care practice (Albert, 1990, Pyke & Bengtson, 1996)

- Communal
- Individualist

Attitude toward exchange (Murstein *et al.*, 1977, Molm, 2003)

- Non-exchange oriented
- Exchange oriented

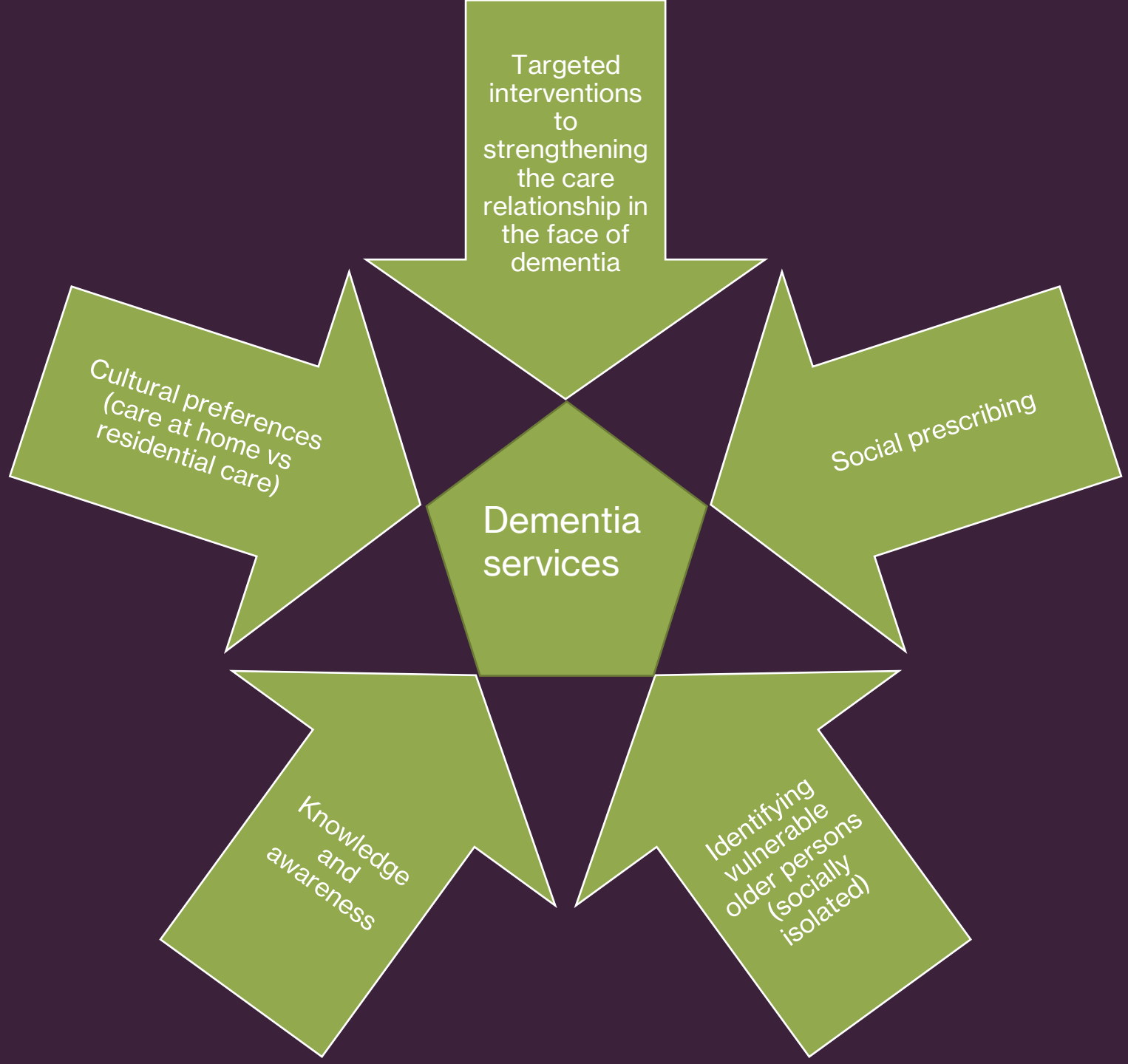
Type of reciprocity (Sahlins, 2017)

- Generalised
- Balanced

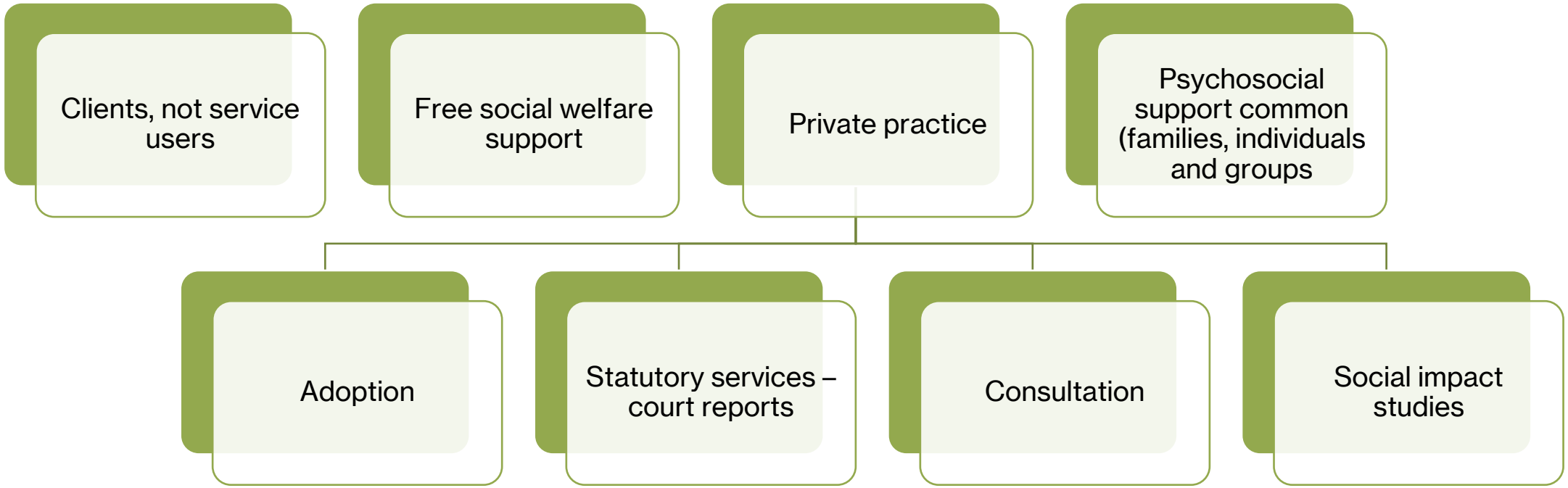
Relationship type (Clark & Mills, 1979, 2012)

- Communal
- Exchange

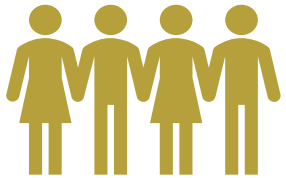
Implications for practice



Social work in SA



Different identities



Low household income

Prior engagement with social services

Not familiar with concept and process of research

Engaging with me as **social worker**

Middle and high household income

No prior engagement with social services

Familiar with concept and process of research

Engaging with me as **researcher**

Role conflict

As a **researcher** – establishing research relationship (time bound), trust, objectivity – **research ethics**

As a **social worker** – establishing social work relationship (ongoing), trust, psychosocial support, available when needed, duty to care - guided by professional **code of conduct**

Reflections

Power dynamics	Renumeration / tokens of appreciation	Taking consent	Recruiting	Anonymity
Dementia / memory difficulty	Normal part of ageing vs disease	Permission to interview other parties	Who silences the voices of PWD	Cultural awareness

Lessons learnt

Role conflict can be a challenge

Reflexivity and positionality

Adaptability – process and personal

In conclusion

“We are hardwired to connect with others, it is what gives purpose to our lives, and without it there is suffering. From the time that we are born we need connection to thrive emotionally, physically, spiritually and intellectually.”

Brene Brown (2010)

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Questions