SURECAN: Meta-ethnography of cultural influences on cancer-related psychological interventions for black and minority ethnic (BME) patients in the UK

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SURvivors' Rehabilitation Evaluation after CANcer

Overall SURECAN Trial Aim…
(SUrvivors' Rehabilitation Evaluation after CANcer)

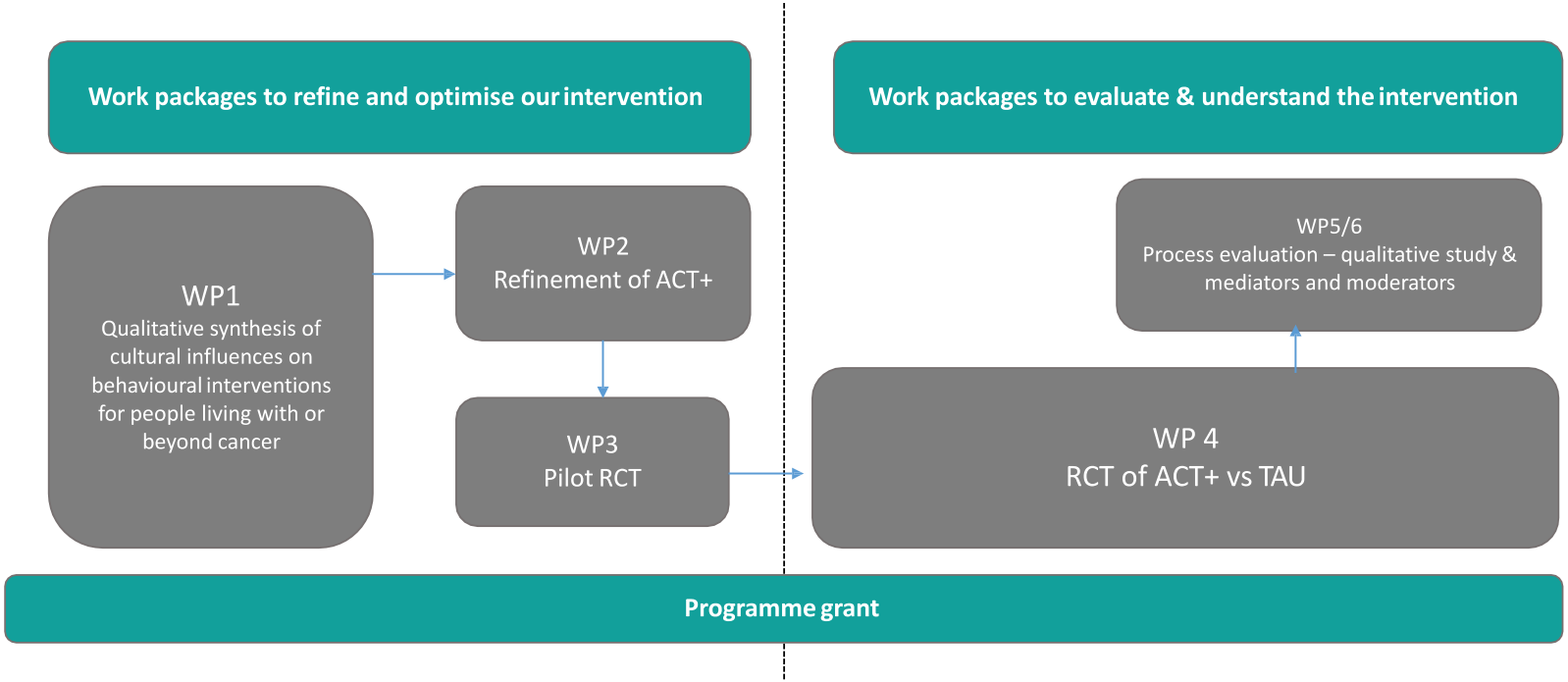
*To **develop, pilot and evaluate** a novel, person-centred, **psychological intervention ("ACT+"),** based on Acceptance and Commitment Therapy*

*for people who have **completed a hospital-based course of treatment for cancer with curative intent***

(head & neck, breast, prostate, colorectal, haematological)

*But who experience **poor quality of life***

Design: Six interconnected work streams



SURECAN meta-ethnography and rationale

- Registered with PROSPERO (register of prospective systematic reviews)
- Meta-ethnography is 7 step methodology widely used in health research (Noblit & Hare 1988), to develop new conceptual insights from qual papers.
- Our focus on cancer services, including survivorship + psychological interventions
- Black and Minority Ethnic (BME) or Black, Asian and Minority Ethnic (BAME) groups present in the UK (namely minority ethnic groups as specified by ONS census).
- Findings inform SURECAN so that therapy can be delivered in more culturally sensitive ways.

Summary of methods

- Searches developed, tested and carried out on major **scholarly databases**
- **11,142** journal paper **abstracts** retrieved and screened independently by 2 researchers
- **84** papers from **2010** onwards reporting UK-based studies subjected to **full text** screening by 2 independent researchers
- **28** papers were eligible for inclusion
- 2 researchers independently extracted and agreed study characteristics
- 3 Researchers independently identified and extracted recurring concepts
- 2 researchers independently assessed the quality of the 28 studies using a Critical Appraisal Checklist
- We are currently developing the **conceptual synthesis**

Background on emerging conceptual framework

- **Relational turn** in the social sciences, psychiatry etc. (Dépelteau 2018)
- Social worlds don't consist of entities to be separated, but are comprised of "mutually constituting relations" (Feldman & Worline, 2016).
- People, materials, ideas and cultures only take on significance through practices that connect them with other things, meaning is not innate to entities, it is emergent (Dépelteau, 2018)
- "Self" an illusion, even biologically (e.g. The Self Delusion, Prof Tom Oliver 2020)
- **ACT** drawn from a philosophy of the inter-relationship of everything (& illusionary nature of self)
- Relationality destabilises the **Individualism** of neoliberal societies.

The key emerging themes

1. Complex and diverse illness attributions
2. Drawing strength from faith, spirituality and religion
3. Sources of support & roles of family
4. Stigma and its consequences
5. (Others not covered due to time limits e.g. language and concepts, relations with practitioners)

1. Complex and diverse illness attributions

- Multiple **explanatory** models, e.g. genetic, lifestyle, social, moral, divine
- These **perspectives** can compete, contrast and interchange even in individuals
- Pts. expect '**pluralistic** approaches to care' and/or 'flexibility in accommodating multiple approaches to their condition'
- Seek range of 'cures'
- Beliefs about the cause(s) of illness affect how people **seek help** e.g. when mental illness seen as spiritual
- Moral and spiritual frameworks common - forces beyond one's immediate **control** (e.g. fate, God's will, punishment, karma, evil, sin)
- **Supernatural** beings feature e.g. sorcery, demonic possession, djinn, evil eye, black magic etc.

1. Complex and diverse illness attributions

[The] medical profession did not have a sufficient understanding of possession, nor is this included as part of their training (Rabiee & Smith, 2014).”

“When you go to hospital and you are a doctor, you can’t understand whether I have a djinn. … Somali doctors specialise in the case of magic…he did his own traditional medicine so can’t ignore these things. In European countries they don’t know about djinn and evil eye, they don’t know they need to recite the Koran.” ***(Male, African, Mental Health)***

[**Djinn** - an intelligent spirit of lower rank than the angels, able to appear in human and animal forms and to possess humans].

2. Drawing strength from faith, spirituality and religion

- Consistently **important** topic across papers - often integral part of life
- **Complex** – Ideas of faith, spirituality, religion, faith communities, prayers, artefacts, healers, leaders
- Provides emotional strength, positivity, support, reassurance, and coping
- A view that strong faith can mean less need for services
- Accessing services could be a ‘betrayal’ of spirituality/religion
- Religious leaders guidance can be preferred over health services

2. Drawing strength from faith, spirituality and religion

It was suggested that religious beliefs promote a ***positive outlook***. Some maintained that religion aids ***acceptance of their destiny*** (Bache et al., 2012).

"I draw strength from it because I sing in the choir and you know I pray a lot and feel calm and feel positive from it. It keeps me sane [it] gives you something to look forward to. I try and sometimes if I'm not feeling so good, I still try and go to the meeting sit down there, others pray and I sort of calm down..." ***(65-year-old female, breast cancer, diagnosed 9 years previously)***

3. Sources of support & roles of family

- **Lay hierarchy** of help-seeking: self – family & friends – wider
- Professional services for the 'serious problems' or if lay network fails
- Family and friends can be a key source of **support**
- Family as a 'safe network' as 'in-house'
- Variations e.g. "strong Black women" & men may be particularly reluctant to access help, those without family especially isolated.
- Family influential in health access - **facilitative** and **regulating** (e.g. South Asian women may need 'permission' to attend).
- Therapy goals may need to adjust to **families**

3. The roles of family

Women found **families supportive, but fearful of having "cancer in the family"**. In some cases there was a great deal of pressure to "keep quiet", not discuss a cancer diagnosis even with immediate family (Barlow and Lloyd-Knight, 2012)

I told my sons and my parents and I just said I've got a lump in my breast. And then my mother said "She's saying she's got cancer," and my father replied "No-body mentions that word in the Asian community." ***(Asian woman, breast cancer, Barts)***

4. Stigma and its consequences

- Stigma frequently '**intense and complex**'
- Families important in managing stigma
- The presence of stigma towards mental illness and cancer.
- Communities integral to support, but also can be dangerous
- Cancer stigma **radiates** - detrimental impact on marriage prospects, can affect the whole family
- **Variations:** Cancer taboos differ amongst various African/Caribbean/Asian communities
- Post-treatment support – risk of disclosure of cancer to 'community grapevine'
- Can delay help-seeking and mean low uptake of services

4. Stigma and its consequences

Whilst some Black African women felt the option to meet other women for ***breast cancer support*** should be available, they also said they would be ***scared or unable to use such a service*** (Tompkins et al., 2016)

"I'm too scared to do it [a support group]. I don't mind, sometimes I think, well, they don't know me, maybe I should go to where they don't know me, but then what happens if you get there and you know somebody there?" ***(Born abroad Black African woman, 51–70 years. 0–6 months post-treatment, breast cancer)***

Practitioner implications

- **BME is not one group (but meta-ethno looks for variation)**
- **Valued approaches**: respect, non-judgement, empathy, listening, being taken at face value, sensitivity to difference **(all relational "goods")** (Donati 2019)
- Useful practitioners navigate their own **social world** into others
- **Visiting social worlds** – important to acknowledge NHS + wider racism, different concepts, different levels of acculturation, migration issues etc.
- **Cultural matching** – may or may not be necessary – patient preference
- **Practitioner awareness of their "positioning"** – important
- **Power** – people want to be helped, not 'done to'
- **Authority** – But some (e.g. especially some South Asian in our sample) may want practitioners to be authoritative (not person-centred)
- **Gender of practitioner** – may or may not matter in interactions
- **Stigma** – will patient even make it to your service (high stakes)?

ANY QUESTIONS?

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