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Intersectional experiences of traditionally marginalised groups

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Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

Institute of Health and Wellbeing
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Foreword

Originally, a project entitled ‘Why are older people living in areas of deprivation under-represented in psychological therapy services? A Critical Realist Framework Analysis grounded in older people’s perspectives,’ was planned to form the Major Research Project chapter of this thesis (see final blind-marked proposal in Appendix 0.1, pp.74-96). An application for ethical approval based on this proposal was completed for the College of Medical, Veterinary and Life Sciences (MVLS) at the University of Glasgow towards the end of February 2020 and was due to be submitted shortly afterwards. However, with the onset of the COVID-19 pandemic, this project could not proceed as planned.

When lockdown measures were introduced in March 2020, the University of Glasgow recommended the suspension of all non-essential research activity. This prevented the completion of the project within the time constraints of the accredited prior learning (APL) training pathway. The original project would have involved individual face-to-face interviews with 10 to 16 older people living in areas of deprivation. Clinically vulnerable groups were advised to ‘shield’ at home between March and July 2020 (Scottish Government, 2020). Evidence suggests that people living in social deprivation are more likely than people living in affluent areas to have multiple health conditions, including COPD and diabetes, with multimorbidity increasing with age (Barnett et al., 2012). These conditions have been found to increase the risk of contracting and dying from COVID-19, therefore face-to-face interviews were deemed unsafe.

Remote interviews via video and telephone were considered. However, this population is known to experience digital exclusion and older people are less likely to own devices required to access interviews in these formats (UK Parliament, 2020). This risked restricting and biasing the available interview sample who did have such devices, which would contradict the aims of the project particularly given that psychological therapy services were also moving towards remote ways of working. Additionally, recruitment relied on community-based organisations, who were required to make significant adjustments to their own operations. It was therefore agreed by the author and her supervisors to abandon the original planned project and identify contingencies.

Prof Hamish McLeod, one of the author's two academic supervisors, obtained an existing dataset for secondary analysis. This led to the development of an alternative project, entitled 'Experiences of Divorced Women Living in Palestine: A Mixed-Method Narrative Analysis,' which is reported in the second chapter of this thesis. The project was developed both independently and in discussion with supervisors (see Appendix 0.2, pp.97-100). Whilst the systematic review and major research project in this thesis now involve two very distinct populations and topic areas, they are united by their application of Intersectionality Theory.

Initially, Intersectionality Theory was developed to explain the experiences of Black women in the USA in relation to workplace discrimination legislation, which treated racism and sexism as mutually exclusive, protecting Black men and white women yet excluding Black women (Crenshaw, 1991). This theory has since been applied in a range of contexts to describe intersecting forms of oppression, including those related to race, gender, age, disability, social class and sexuality. A growing body of evidence suggests that having more

than one traditionally marginalised identity is detrimental to psychological wellbeing and help-seeking (Seng et al., 2012; Tang & Pilgrim, 2017; Vu et al., 2019). Whilst these variables are not modifiable by traditional Clinical Psychology approaches, they are important for understanding the wider structural context within which people experience psychological difficulties and can indicate areas for service development, leadership, and political engagement within the profession. In this thesis, Intersectionality Theory is applied to understanding service-related experiences of gay and lesbian carers of people living with dementia, and the experiences of divorced women living in Palestine.

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Chapter 1: Service-Related Experiences of Gay and Lesbian Carers of People Living with Dementia: A Systematic Review.

Prepared in accordance with the author requirements for the
journal *Dementia* (Appendix 1.1, p.101).

Abstract

Introduction: Evidence suggests that lesbian, gay, bisexual, transgender, queer + (LGBTQ+) adults experience difficulties accessing person-centred health and social care. Experiences of social exclusion may place additional strain on LGBTQ+ carers compared to heterosexual or cisgender counterparts and intersect further with the stigma of dementia. This review aimed to synthesise service-related experiences of LGBTQ+ carers of people living with dementia.

Method: Seven electronic databases were systematically searched. Two journals were hand-searched. Reference list and forward citation searches were conducted on included papers.

Results: 325 records were screened. A total of 10 papers were eligible for thematic synthesis and quality appraisal. Only gay and lesbian carers were represented in included studies. Synthesis identified three central themes: ‘Intersecting forms of discrimination’, ‘(Loss of) control over the disclosure process’ and ‘Diverse support needs and preferences.’

Conclusions: Intersecting forms of discrimination, including explicit homophobia and implicit heteronormativity, can increase burden on gay and lesbian carers of people living with dementia. Control over the disclosure process is important to many carers but can be lost as the cared for person’s dementia progresses. Gay and lesbian carers have diverse support needs and preferences, indicating service development is needed to provide safe and inclusive spaces. Further research is required to enrich understanding in this area and should include racially, culturally and socially diverse (LG)BTQ+ carers of people living with dementia.

Background

Lesbian, gay, bisexual, transgender, queer + (LGBTQ+)¹ communities are known to experience various health inequalities (Zeeman et al., 2019). Some people avoid disclosing their sexuality or gender identity to healthcare professionals for fear of discrimination and to avoid detrimental effects to quality of care (Brooks et al., 2018). Older LGBTQ+ people may be at further social disadvantage due to historical experiences of social-structural discrimination in the UK, with homosexuality being both criminalised until 1967 and officially pathologized until 1973 (Almack & King, 2019).

Although often considered a singular group or community, the LGBTQ+ population is highly heterogeneous and there are a diversity of strengths, needs and challenges experienced by the individuals within (Fredriksen-Goldsen et al., 2014). For older LGBTQ+ people living with dementia, the intersection between sexuality, gender, age and disability could contribute to multiple forms of stigma and exclusion, and additional facets of identity related to socioeconomic status, race and ethnicity may contribute further (Adelman, 2016; Crenshaw, 1991). Older people may be excluded by the LGBTQ+ community due to ageism, people living with dementia may be excluded by the older LGBTQ+ community due to ableism, and the older community may exclude LGBTQ+ people due to heteronormativity and cisgenderism (Baril & Silverman, 2019). Older LGBTQ+ people are also more likely than the general older population to live alone, be single and have no children (Fredriksen-Goldsen, et al., 2013). These social-structural factors increase risk of isolation and places greater burden on friends and partners to provide care, which may in turn marginalise them as carers.

¹ LGBTQ+ is a broadly inclusive umbrella term which includes individuals who identify as non-binary, intersex, agender and gender-fluid (Westwood et al., 2020).

Carers of people living with dementia have been found to have negative physical and mental health outcomes, and greater perceived healthcare needs than non-carers (Bremer et al., 2015). In addition to poor quality of life, carers of people living with dementia have also been found to have poorer experience of care services than non-carers (Thomas et al., 2015). A systematic review identified the need for carers of people living with dementia to have access to person-centred peer and professional support in their role (Cross et al., 2018). Recent legislation, such as the Carers (Scotland) Act 2016 which came into effect in April 2018, entitles carers to an assessment of needs and involvement in carers services, among other statutory rights.

However, there are various potential barriers to LGBTQ+ carers of people living with dementia accessing supports. A study conducted in Ireland (Sharek et al., 2014) found that many older LGBTQ+ people lack trust in healthcare professionals' awareness of issues affecting minoritized sexual and gender identities, and do not feel that their relationships are respected. A study exploring the healthcare experiences of LGBTQ+ adults (Romanelli & Hudson, 2017) found that many services are not representative of these communities, and that they are not equipped to meet needs in a person-centred manner, which in turn restricted willingness and ability to access and engage with healthcare services. Further investigation is required to explore how services could develop awareness around supporting LGBTQ+ carers of people living with dementia, taking into consideration the diversity and complexity of each person's needs and experiences (Westwood et al., 2020). Discovery-based methods within qualitative research are well-placed to develop understanding in this area.

Aims

A modest but growing body of qualitative studies describe the perspectives of LGBTQ+ carers of people living with dementia but has yet to be systematically reviewed. This review aims to synthesise and appraise the quality of evidence on the health and social care service-related experiences of LGBTQ+ carers of people living with dementia, and to identify areas for future research and service development.

Method

Search Strategy

The following electronic databases were searched for all dates up to 6th August 2020: MEDLINE (EBSCO), PsycINFO (EBSCO), Social Policy and Practice, CINAHL (EBSCO), Social Sciences Citation Index (SSCI), Applied Social Sciences Index and Abstracts (ASSIA), and ProQuest Dissertations & Theses. Given variations in qualitative indexing which may compromise the sensitivity of electronic searches, both *Dementia* and the *Journal of Gay & Lesbian Social Services* were hand searched (Wagner et al., 2020). Forward and backward citation searches of included articles were conducted, reference lists searched, and key authors contacted, to identify other potentially relevant articles overlooked by electronic searches.

Search terms were developed using PICOS (Population, Intervention, Comparison, Outcome, Study type) to maximise sensitivity of database searches (Methley et al., 2014). They were mapped onto MeSH subject headings for each database (Appendix 1.2, p.102, shows one full PsycINFO search). The following master terms were used:

1. LGBTQ+: Lesbian* OR Gay OR “Same sex” OR Homosexual* OR Bisexual* OR Transgender* OR Transsexual* OR Agender OR Non-conforming OR Non-binary OR Queer* OR Genderqueer OR Intersex* OR Asexual* OR LGB*

AND

2. (People living with) Dementia: Dement* OR Alzheimer* OR “Lewy bod*” OR Frontotemporal OR “AIDS Dementia” OR “HIV-associated Dementia” OR Senil* OR DAT OR VCI OR Pick* OR FTD OR YOD OR EOD OR Korsako* OR Huntington*

AND

3. Qualitative Study: Qualitative OR Interview* OR “Focus Group*” OR Experience* OR Perspective* OR Narrative OR Thematic OR Grounded OR Phenomenol* OR Ethnograph*

Eligibility Criteria

All qualitative studies published in English were eligible for inclusion. Theses and dissertations were included to improve the breadth of available information on this under-researched topic.

Search Process

325 citations were identified, 109 of which were duplicates, and 195 of which were excluded during initial screening (Figure 1). Twenty-one full text articles were reviewed and nine met inclusion criteria. One further study was identified by forward citation search of included studies, for a total of 10 included in review and synthesis.

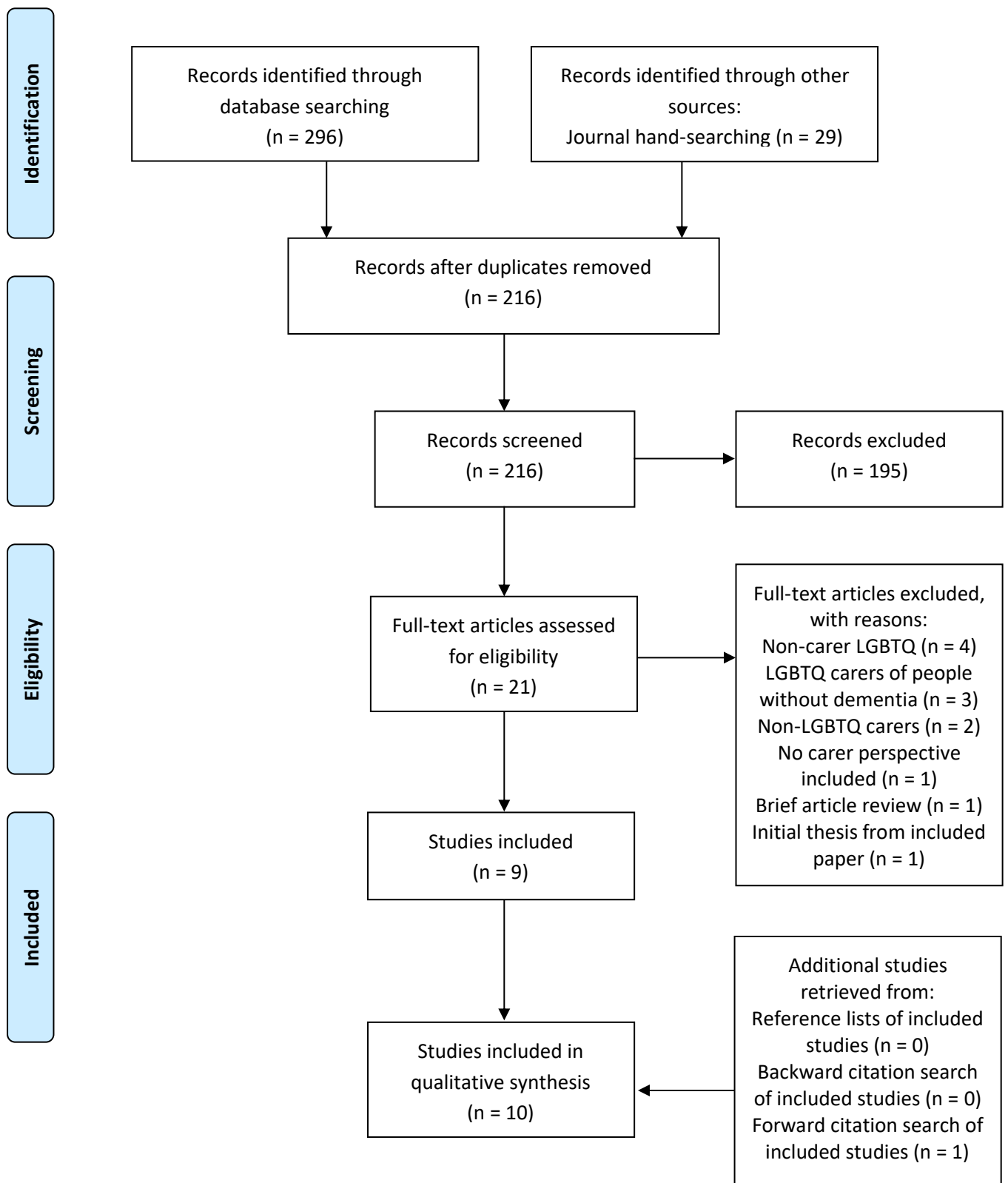


Figure 1. PRISMA Flow Diagram (from Moher et al., 2009)

Data Synthesis

Data relevant to review aims were manually extracted. Thematic synthesis was selected based on the heterogeneity of the population, broad range of methodologies under review and the aims of understanding shared and divergent service-related experiences (Barnett-Page & Thomas, 2009), following this process: (1) line-by-line coding and charting; (2) descriptive theme development grounded in data; and (3) analytic theme development grounded in review aims (Thomas & Harden, 2008; Appendix 1.3, p.103).

Quality Appraisal

The Critical Appraisal Skills Programme (CASP) Qualitative Appraisal Tool (2018) was selected for this review due to its straightforward application and ease of use for novice researchers (Majid & Vanstone, 2018). A random sample of included studies (N = 3) were co-rated by an independent reviewer (Trainee Clinical Psychologist). There were small areas of disagreement relating to appraisal of rigour but following discussion consensus was reached and no further co-rating was required. No studies were excluded on the basis of quality appraisal, but the impact of quality was considered regarding transferability of findings (Thomas & Harden, 2008).

Reflexivity

Both thematic synthesis and critical appraisal involve subjective judgement and interpretation, therefore are influenced by the researcher's perspectives and experiences, in line with critical realist epistemology (Barnett-Page & Thomas, 2009). A reflective log and research supervision were used to acknowledge and reflect upon biases arising during the review process to mitigate their impact on findings.

Results

Study Characteristics

Data from a total of 78 carers was available from across 10 included papers. Papers originated from a range of Western countries representing various health and social care systems and contexts. All participants identified as gay men or lesbian women, with no bisexual, transgender or other LGBTQ+ identities represented (Table 1).

Table 1: Study characteristics.

Authors & Year of Publication	Country	Population & Number of Participants*	Data Collection	Methodology/ Analysis	Research Questions/Aims	Themes
Barrett et al., (2015)	Australia	27: gay male and lesbian partner-carers (split NR).	In-depth interviews F2F/Skype Member reflections sought.	<ul style="list-style-type: none"> • Thematic analysis. • Epistemology NR. 	To interview “LGBTI people and their partners about their experiences of living with dementia, their needs and their suggestions for the education of service providers”.	<ul style="list-style-type: none"> • Impacts of dementia on sexual orientation and gender identity • Conflict with families of origin • Managing disclosure • Intimate relationships and other safe spaces • The importance of inclusive services
Constable (2011)	England	3: 1 gay male friend-carer, 2 lesbian daughter-carers.	Semi-structured interviews F2F Member reflections sought.	<ul style="list-style-type: none"> • Analysis of Narratives/ Framework Approach. • Biographical/ person-centred epistemology. 	“What are the experiences of caring for someone with dementia?”	<ul style="list-style-type: none"> • The experience of caring • Changes/enduring aspects of relationships • Coping approaches • Beliefs about caring • Carers’ support systems • Quality of support provided to carers
McParland & Camic (2018)	England	9: 5 lesbian and 3 gay male partner-carers, 1 lesbian friend-carer.	Semi-structured interview F2F (6), and Skype (3)	<ul style="list-style-type: none"> • Interpretive phenomenological analysis. • Critical realist epistemology 	“What is the experience of dementia for LG individuals and their significant others? How is this experienced relationally, within partnerships and other significant relationships?”	<ul style="list-style-type: none"> • Duality in managing dementia • Giving yourself away vs holding onto yourself • Relationships as sheltered harbours
Meadows et al. (1999)	England	8: 6 gay male partner-carers; 2 gay male friend-carers.	Semi-structured interview F2F.	NR	To understand caregiver burden in HIV-associated dementia and specific issues affecting service and support provision.	<ul style="list-style-type: none"> • Problems of dementia • Problems of caring • Service use • Suggestions for service development
Moore (2002)	USA	7: 5 lesbian and 2 gay male partner-carers.	NR	NR	To report the major themes that emerged from telephone support group sessions.	<ul style="list-style-type: none"> • Prior experience with support groups • Antipathy of medical and human service providers • Legal and financial issues • Anger: past, present and future • Anticipatory grief • Struggle with forgiveness and closure

O'Connor et al. (2010)	Canada	1: lesbian partner-carer	5 in-depth interviews with case study participant. 1 family interview with partner-carer and daughter.	<ul style="list-style-type: none"> • Discourse, narrative and thematic analysis. • Biographical case study epistemology 	To “develop a textured account of how different identities can work together and in opposition to shape the dementia experience.”	<ul style="list-style-type: none"> • Making sense of the dementia • Being taken seriously • Being ‘skipped over’
Price (2010) **	England	21: 8 lesbian daughter-carers, 2 lesbian family-carers, 1 lesbian partner-carer; 8 gay son-carers, 2 gay friend-carers.	Semi-structured interviews F2F. Member reflections sought.	<ul style="list-style-type: none"> • Constant comparative thematic method. • Epistemology NR 	To understand “the experience of coming out to service providers.”	<ul style="list-style-type: none"> • Active disclosure • Passive disclosure • Passive nondisclosure • Active nondisclosure • Outed by dementia
Price (2011) **	England	8 lesbian daughter-carers from above sample.	As above.	As above.	To understand “strategies lesbian carers used to negotiate the complex and contested category of the ‘family’ in the context of their care-giving experiences.”	<ul style="list-style-type: none"> • Negotiating care-giving relationships within the biological family • Support from within: the family of choice
Price (2012) **	England	Same as Price (2010).	As above.	As above.	To understand how “caring experiences have influenced expectations of how carers’ own health and social care needs may be met as they age and their concerns and anxieties about the future in this context.”	<ul style="list-style-type: none"> • Living in the shadow of dementia • Specialist provision
Reczek & Umberson (2016)	USA	2: gay spousal son/in-law-carers	Separate in-depth semi-structured interviews. F2F.	<ul style="list-style-type: none"> • Thematic analysis. • Epistemology NR 	To explore “the dynamics of spousal support provision within gay, lesbian, and heterosexual marriages wherein at least one adult child performs intergenerational caregiving.”	<ul style="list-style-type: none"> • Spousal (lack of) support for parental caregiver • Spousal (lack of) support for in-law caregiving • Marital dynamics while caregiving in coresidence

*Relevant to this review. See Appendix 1.4, p.104, for additional participants.

**Papers derived from a single qualitative study reported in an unpublished PhD thesis.

F2F=Face to face. NR=Not reported. Unless otherwise stated, data collection was based on standalone interviews.

Thematic Synthesis

Synthesis of available data from gay and lesbian carers contributed to the development of three analytic themes relevant to the aims of this review, presented here with selected illustrative quotes from included studies (see Appendix 1.5, pp.105-107 for process).

Intersecting forms of discrimination. Being a gay or lesbian carer of a person with dementia was described as a “double stigma” (participant; McParland & Camic, 2018, p.460) and a “double whammy” (participant; Barrett et al., 2015, p.36). Multiple intersecting forms of discrimination were evident, with the ageist erasure of sexuality in some older people’s services and the sexist assumption that lesbians without children are “available to care” (participant; Price, 2011, p.1293). Some carers anticipated intersecting forms of discrimination whereas others experienced it first-hand:

“The next morning the same caregiver overheard the nursing students chuckling in the hallway, ‘In this room we have a pair of old gray lesbians.’ Their attitude was that older lesbians shouldn’t be affectionate with each other, as if ‘after 50, passion, caring, and tenderness dry up.’ She noted that being an older lesbian is frightening because ‘physicians and nurses see us differently’.” (‘participant’/author; Moore, 2002, p.31).

Whilst some carers experienced explicit homophobia, others described the harmful effects of services assuming that a heterosexual orientation is the default norm. This heteronormativity made some gay and lesbian carers feel excluded from services and impacted on some carers accessing support they needed to manage the caring role:

“Nick [...] expressed concerns about accessing respite services for his partner because ‘a lot of them are ... religiously run and ... cater to the heterosexual who have got kids, grandchildren, things like that’. The fear of discrimination resulted in delays accessing services.” (‘participant’/author; Barrett et al., 2015, p.37).

Even when carers did access services, some encountered barriers to accessing personalised support. Heteronormative assumptions prevented some services from recognising, assessing or meeting the unique needs associated with being a gay or lesbian carer. This served to make some carers feel invisible within services:

“...the acting carer support manager said immediately, in response to me saying I was gay ‘Well we treat everyone the same, you won’t find anyone who is prejudiced at the Alzheimer’s Society’ and I thought ‘Er, well, I should hope not, but that wasn’t exactly what I was saying – er – I do have some other needs actually, which are not the same as a husband or wife etc.’ Anyway, I bit my tongue because I couldn’t really articulate, to her, what her remarks signified.” (participant quote; Price, 2010, p.163).

These findings indicate that many gay and lesbian carers in included studies both anticipated and experienced intersecting forms of discrimination from services, including explicit homophobia or implicit heteronormativity. The above example suggests that some services may not be aware of the harms of heteronormativity towards carers, increasing existing burden on individual carers to educate and inform.

(Loss of) control over the disclosure process. Many carers described careful consideration around disclosing gay and lesbian identities to services. Clear signs that disclosure of gay and lesbian identities will be well-received are described in one paper as “safety signals” (author; McParland & Camic, p.466). In their absence, carers can feel anxious and uncertain about the reaction they will receive in support groups:

“I recognized quickly I was different. I just froze. Should I tell them about my partner? [...] What should I do or say? All I knew was how we have tried to be discreet and quiet about our private lives all these years.”

(participant; Moore, 2002, p.29).

However, some carers experienced clear signs that disclosure would not be well-received. This led some to conceal their sexuality and remain in the group at the expense of hiding relationships and lives outside the group, whilst others chose to leave groups where they felt a lack of belonging as a form of self-preservation:

“...the real possibility of having to go through the coming out process each time the group membership altered was not a viable option, as it would take, she said, too much emotional energy that might be better spent on the rigours of caring.” (author; Price, 2010, p.165).

In the past, some carers described having managed a homophobic society by living privately and avoiding contact with others, including services. However, for many carers, the demands of their role and the person with dementia’s need for support necessitated service involvement. Some carers described changes in their relationship

with their partners with dementia due to perceived consequences of disclosing and openly expressing sexual identities in some service contexts:

“[Tim] recalled how Patrick ‘became more closeted’ when he entered residential aged care because he was concerned about discrimination. [...] Tim described how a lack of privacy and concerns about homophobia made it difficult for him to spend time alone with [Patrick].” (‘participant’/author; Barrett et al., 2015, p.35).

However, some carers lost control over the disclosure process due to cognitive changes in dementia. Some people became increasingly disinhibited as dementia progressed, whilst others began to misidentify paid carers from services. This was anxiety-provoking for carers who feared the consequences of inadvertent disclosure:

“Lidia described how her partner was ‘not as aware’ as she had been previously, and she worried that her partner’s affectionate nature might be ‘misinterpreted’ by a female carer.” (‘participant’/author; Barrett et al., 2015, p.36).

These findings indicate that control over the disclosure process can be important for many carers. Decisions to disclose gay and lesbian identities could depend on the perceived safety of the service context. However, some carers can lose control over this process due to changes associated with dementia.

Diverse support needs and preferences. Some services may have difficulties identifying and meeting the needs of gay and lesbian carers of people living with dementia. As noted above, this could relate to heteronormativity with some services believing they should “treat everyone the same” (participant; Price, 2010, p.163) regardless of sexuality, or some people deciding to “become more closeted” (participant; Barrett et al., 2015, p.35) when accessing services for fear of discrimination. However, some carers refused to compromise expression of gay and lesbian identities in exchange for accessing services:

“I spent my life fighting to get out of the closet. I’m not going back into the closet. I want to be able to talk to you if you’re sitting next to me about how I’m sad because I’ve lost the man in my life who is important to me. I don’t want to have to talk in language that doesn’t cause offence.” (participant; Price, 2012, p.526).

Instead, some carers described a preference for services designed specifically with the needs of gay and lesbian carers, and people with dementia, in mind. Among carers with these preferences, they described a need for safety to express sexual identity without fear of discrimination or judgement, and a desire to move away from the heteronormative assumptions that can be encountered in some mainstream services:

“I do strongly believe that we need to have special acknowledgement that in our society we are not ‘the same’ and that we need spaces where we can get together [...] there’s something about being in a majority, sharing a culture, not having to explain, having the same reference points etc., which straight people never even think about because for them it’s the norm. We should

not have to justify wanting this contact with other gay people other than to say we enjoy it!” (participant; Price, 2012, p.525).

Conversely, some carers reported positive experiences of mainstream services. One carer described experiencing a “real warmth and camaraderie” (participant; Barrett et al., 2015, p.37) within a carer’s group, which facilitated a sense of belonging. Another couple “continued receiving a warm welcome” (author; McParland & Camic, 2018, p.466) following disclosure within a carer’s group, which signalled acceptance.

However, these positive experiences were reported by a relative minority. Many carers identified the need for mainstream services to become more explicitly inclusive:

“A kite mark [...] would indicate that staff have been made aware of LGBT clients and would indicate that prejudice of any kind would not be tolerated. That would make me feel safe and confident.” (participant; Price, 2012, pp.528-529).

Some carers were more optimistic than others about inclusive mainstream services. For some, this related to preferences for more tailored services gay and lesbian carers as noted above, but for others it appeared to reflect the need for broader sociocultural and structural progress in relation to perceptions of gay and lesbian identities, rather than on an individual service basis:

“I think it’ll be many years before mainstream services are gay friendly, lesbian and gay friendly. In fact, it will need the whole world to change to

sort out homophobia from other residents in the homes.” (participant; Price, 2012, p.528).

These findings indicate that gay and lesbian carers have a diverse range of needs and preferences for accessing and engaging with supports, whether more inclusive mainstream services or more tailored, community-specific specialist services. These needs and preferences may vary based on the generational cohort of carers and the cared for people with dementia and will be restricted by what is locally available.

Quality Appraisal

Credibility, rigour and transparency of each paper were considered using CASP (2018) Qualitative Checklist criteria (see Appendix 1.6, p.108). Overall, papers included clear aims and statements of findings, leading to relevant discussions with a range of clinical practice implications and, in some cases, recommendations for future research. Three papers (Price, 2010; Price, 2011; Price, 2012) were aggregates of a sample from a single study, which increases the risk of over-representing data generated from these carers, although their aims were sufficiently different to warrant in-depth exploration. Three papers, including a thesis, clearly reported and justified their data collection approach and procedures (Constable, 2011; McParland & Camic, 2018; O’Connor et al., 2010). However, opaque reporting obscured many details around data collection, analytic method and epistemological stance, limiting appraisal of rigour and credibility.

Most papers considered the relationship between researcher and participants to an extent and some used strategies such as member reflections and independent researcher checks to enhance credibility, but processes of reflexivity were only made explicit in two papers (Constable, 2011; McParland & Camic, 2018). No papers discussed saturation or sufficiency of their data, which may relate to difficulties with recruitment (e.g., Price, 2010). All participants eligible for this review identified as lesbian women and gay men, with none identifying as bisexual, trans(gender) or queer. Only one paper reported attempts to recruit trans(gender) people (Barrett et al., 2015), limiting transferability within the broader LGBTQ+ community. Although wide-reaching purposive and snowball recruitment strategies were used in most studies (excluding Moore, 2002), all participants, excluding the single case reported in O'Connor (2010), were from white, middle-class, highly educated backgrounds, limiting transferability.

Discussion

This review aimed to synthesise research on health and social care service-related experiences of LGBTQ+ carers of people with dementia, and to identify areas for future research and service development. Ten papers were included following a systematic search process, with a total of 78 eligible participants, all of whom were identified as either gay cis-men or lesbian cis-women. Therefore, this review cannot be said to represent the diverse range of identities within the LGBTQ+ community, narrowing from the original aims to focus only on gay and lesbian carers of people living with dementia. Thematic synthesis resulted in three overarching analytic themes: 'Intersecting forms of discrimination', '(Loss of) control over the disclosure process',

and ‘Diverse support needs and preferences.’ Quality appraisal identified strengths and limitations which will be discussed in the context of transferability of these findings.

Intersecting forms of discrimination

Existing literature has highlighted the various physical, emotional and mental burdens on carers of people living with dementia, and the impact this has on accessing and engaging with support (Bremer et al., 2015; Thomas et al., 2015). Both gay and lesbian carers in the included studies reported similar difficulties, but in addition described a “double whammy/stigma” (Barrett et al., 2015, p.36; McParland & Camic, 2018, p.460) associated with gay and lesbian identities and with caring in the context of dementia. This phenomenon is in line with Intersectionality Theory (Crenshaw, 1991), and has been proposed in relation to people living with dementia (Baril & Silverman, 2019). One study (Price, 2011) also indicated the potential for lesbian carers to be further disadvantaged by traditional female gender roles and the expectation of availability to care. These intersecting disadvantages contributed to a sense of isolation among some carers and limited access to and engagement with formal and informal support options, thereby increasing the burden on gay and lesbian carers of people living with dementia.

Many carers described experiences of discrimination by services, including homophobia and service exclusion (Barrett et al., 2015; McParland & Camic, 2018; Moore, 2002; Price, 2010). These experiences appeared to have been internalised by some carers, leading them to anticipate discrimination from others to the extent that it affected their willingness to access or engage with supports and services. The Minority Stress Model (Meyer, 2003), which was developed using evidence from lesbian, gay

and bisexual (LGB) adults, proposes that distal and proximal ‘minority stress processes’, such as past experiences of discrimination and current expectations of rejection, influence mental health outcomes. The model highlights the mediating role of different forms of ‘minority status’, including race/ethnicity and gender, although does not explain how holding multiple minoritized statuses could intersect to increase discrimination and impact on outcomes, as indicated by this review’s thematic synthesis. Additionally, whilst this model focuses on explicit stressful ‘prejudice events’, such as homophobia, the thematic synthesis suggests that discrimination can take both explicit forms, in terms of homophobia, and implicit forms, in terms of heteronormativity.

Service-wide heteronormativity has been found to impact on staff confidence to speak about and meet the needs of the LGBTQ+ community (Kilicaslan & Petrakis, 2019), which could negate opportunities for inclusion, potentially perpetuating LGBTQ+ carers’ lack of trust in staff and sense of invisibility (Utamsingh et al., 2016). However, evidence suggests that same-sex relationships are becoming more publicly normalised in Western societies (Roseneil et al., 2013). Therefore, experiences of gay and lesbian carers may change as society and services become more aware and inclusive of the LGBTQ+ community, perhaps reflecting cohort effects as subsequent generations age.

(Loss of) control over the disclosure process

Engagement with services and supports has been found to require carers to negotiate a complex decision-making process around disclosing their identities and relationships, deploying various strategies depending on the situation (Price, 2010) and presence of

“safety signals” (McParland & Camic, 2018, p.466). Carers of people living with dementia have been described as the “invisible second patients” (Brodaty & Donkin, 2009, p.217) due to the lack of focus on their needs. Findings of this thematic synthesis demonstrate that in circumstances where carers felt unable to disclose their gay or lesbian identities to services, it could mean that opportunities for personalised support as carers were lost. Another systematic review found various barriers and facilitators which influence these decision-making processes, related to the moment of disclosure, perceived outcome of disclosure, healthcare-professional factors and environmental factors (Brooks et al., 2018). Whilst services cannot directly influence internalised perceptions of gay and lesbian carers, thematic synthesis suggested that using inclusive language, challenging heteronormative assumptions, showing acceptance through non-verbal cues, and providing an accepting environment, could all be means of facilitating a sense of safety around disclosure. However, synthesis also suggested that lesbian and gay carers may lose control over the disclosure process as the cared for person’s dementia progresses and they become disinhibited. This was distressing for gay and lesbian carers in heteronormative service contexts when there was uncertainty about the response from staff, or explicit homophobia experienced from other residents.

Diverse support needs and preferences

Unsurprisingly given intersecting discrimination experienced by gay and lesbian carers, which can in turn influence decisions and comfort around sexual identity disclosure, thematic synthesis identified that carers have a diverse range of support needs and preferences. Some carers felt that services had not met their needs, either because they were overlooked or because disclosure felt unsafe. However, a minority of carers reported feeling included and accepted within mainstream carer’s groups (Barrett et al.,

2015; McParland & Camic, 2018). Some gay participants reported a preference for support from others within their community, to feel a sense of belonging and to express themselves openly (Constable, 2011; Price, 2012). Whilst research in this domain is restricted, potentially reflecting the lack of such services, evidence suggests that 'LGBT' staff can facilitate sexual orientation disclosure in healthcare settings (Brooks et al., 2018). Other participants, including gay men and lesbians, wished for more inclusive mainstream services and changes in wider society to support this. One participant felt that it was unrealistic to hope for services to become more inclusive primarily because of other older service users with homophobic attitudes (Price, 2012). As above, there may be cohort effects reflecting change in this respect as the LGBTQ+ community are afforded greater rights and respect in society.

Strengths and Limitations

Only ten papers with a total of 78 carers of people living with dementia could be found with systematic search procedures, indicating the limited range of available research on this topic. All studies included carers who identified as either gay cisgender men or lesbian cisgender women, thereby failing to capture experiences, needs and preferences of carers from BTQ+ communities. Apart from one participant, studies represented white, middle-class and highly educated carers, which limits the transferability of these findings to carers from other racial, ethnic and social backgrounds. However, as the findings of thematic synthesis refer to intersecting forms of discrimination, (loss of) control over the disclosure process, and diverse support needs and preferences, these principles may be somewhat transferable. Lack of transparency in reporting details of data collection, analytic methods and epistemological stance in half of the studies prevents future research from being influenced by their design. A lack of information

on the cared for people with dementia precludes understanding of the needs of different groups, for example carers of people with young onset dementia.

This is the first systematic review of service-related experiences of gay and lesbian carers of people living with dementia, to the author's knowledge, thereby building on and lending perspective to existing literature. The use of thematic synthesis enabled this review to both synthesise and 'go beyond' the findings of the included studies to generate analytic themes relevant to its aims, facilitating both conceptual integration and innovation (Thomas & Harden, 2008). The CASP Qualitative Checklist allowed for consideration of the credibility, rigour and transparency of each paper as a novice researcher, and independent co-rating demonstrated a strong level of agreement to suggest the appraisal was reliable.

Papers were derived from a range of Western cultural contexts from Australia, England and the USA, which each have different health and social care service models. Only studies published in English were included, which introduced cultural bias into the findings. Although efforts were made to develop an inclusive and sensitive search strategy, one paper (Reczek & Umberson, 2016) was only detected following forward citation searching and full-text review. This may reflect the specific topic of this review, carers of people with dementia, which was not explicitly referred to in the title or abstract of the newfound study and was only identified from full-text screening.

Additionally, due to the limited availability of research on this topic, partners, friends and adult children-carers of people living with dementia were effectively merged for the purposes of thematic synthesis. The nature of relationships could have important implications for service-related experiences among carers, and further research is required to enrich understanding in this area (Anderson & Flatt, 2018). Efforts were made to highlight differences between gay men and lesbian women in thematic synthesis, but the scope to broaden this analysis was limited by the availability of data.

Clinical Implications and Research Recommendations

Given the influence of intersectional discrimination and implicit heteronormativity on service-related experiences of gay and lesbian carers in this review, efforts to change service and organisational cultures are indicated to promote inclusion and move away from ‘treating everyone the same’. This could include training, policies and practices to ensure that services can identify needs and provide tailored support to LGBTQ+ carers. Visibility of LGBTQ+ people in promotional imagery, use of inclusive language in written information and on contact forms, and using a visible ‘kitemark’ could help address heteronormativity and cisgenderism in services. Doing so would require investment from leadership structures to support implementation and ready staff for evidence-based practice change (Caldwell et al., 2008; Williams et al., 2020). Research on barriers and facilitators to changing heteronormative practice in health and social care services is indicated. Whilst some carers experienced belonging in mainstream services, others expressed a desire for mainstream services to be more inclusive, and some preferred supports specifically for gay and lesbian carers. Exploring support preferences in practice and offering choice based on local availability could help carers

access services that meet their needs. Further research is indicated given the variation in service preferences.

Further research to identify the experiences and needs of carers of people with dementia who identify as trans(gender), queer, non-binary, intersex and bisexual is required, as well as LGBTQ+ carers from more diverse racial, cultural and socioeconomic backgrounds to understand intersectional service-related experiences. Research on the impact of specific dementia sub-types, such as young onset, on carers may be helpful to refine understanding of support needs. As LGBTQ+ carers may be related to the person living with dementia in various ways, further research could explore the differences in these experiences, for example partners and friends. Further research is required to elucidate service-related experiences of LGBTQ+ people with dementia, perhaps using methods such as walking interviews or arts-based approaches to facilitate participation (Constable, 2011). Future qualitative research should adhere to transparent reporting conventions to allow for appraisal of rigour and credibility.

Conclusions

Gay and lesbian carers of people living with dementia share many of the challenges, burdens and harmful physical and mental health outcomes of their heterosexual counterparts, but many also experience intersecting forms of discrimination, including explicit homophobia and implicit heteronormativity. Control over the disclosure process is important to many carers but can be lost as the cared for person's dementia

progresses. Gay and lesbian carers have diverse support needs and preferences which risk being ignored. Further research is required on the service-related experiences of LGBTQ+ carers of people living with dementia, especially as existing studies are based solely on cisgender gay and lesbian carers from racially and socially privileged backgrounds, and do not include perspectives of bisexual, trans(gender) or queer carers.

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Chapter 2: Experiences of Divorced Women Living in Palestine: A Mixed-Method Narrative Analysis

Prepared in accordance with the author requirements for the
journal *Feminism & Psychology* (Appendix 2.1, p.110).

Plain Language Summary

Understanding the Experiences of Divorced Palestinian Women

Background: Palestine is a predominantly Muslim country. Its existence as a nation is contested by neighbouring Israel, which has led to ongoing conflict. Women living in Palestine marry at a younger age than men and cannot seek divorce without the agreement of their husbands. Little research has been done to understand the experiences of divorced Palestinian women. One study found that among 16 divorced Palestinian women in Israel, many were domestically abused, had little freedom in their marriage, and their lives following divorce varied depending on their living and family circumstances (Meler, 2013). Another study, conducted over 20 years ago, found that divorced Muslim women in Israel felt excluded by others in their community and became isolated at home (Cohen & Savaya, 1997). Hence, reactions to divorced status may substantially impact on the emotional wellbeing of Palestinian women.

Aims: This study aimed to understand how divorce changes the lives and wellbeing of women living in present-day Palestine, and how changes might differ among women depending on their living and family circumstances. Finally, it aimed to consider ways in which Palestinian researchers could continue to understand divorced women and other groups who have been or are excluded from public life in Palestine.

Methods: The researcher was given permission to work with anonymous information that had already been collected from divorced women living in Palestine. This included statistical information from a survey completed by 93 divorced women and a written

transcript of a single interview between a Palestinian researcher and a divorced woman, which was translated from Arabic into English. An approach called ‘narrative analysis,’ was used to develop a story from the interview transcript about how divorce had changed one woman’s life. Main ideas from her story were compared with the survey information to understand similarities and differences between divorced women.

Main Findings and Conclusions: Divorce helped the interviewed woman to escape an isolating, abusive marriage and live a more personally meaningful life. She had a supportive family and lived in an area where opportunities for work and study were available. Around half of the 93 surveyed women also experienced domestic abuse in their marriage and expected to find more freedom in divorced life. More than half reported that their families stood by their decision to divorce. However, many lived in villages or refugee camps and may not have had access to the same work or study opportunities as the interviewed woman. It was difficult to determine whether women experienced freedom in divorced life and what that meant to them with the available information. Further research will help build on these findings. Palestinian researchers are encouraged to develop methods that help them gather information relevant to the lives of divorced women and other groups.

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Abstract

Introduction: Research involving divorced Palestinian women is limited. Previous studies found some women seek divorce due to domestic abuse and lack of autonomy, and that previous generations experienced social exclusion. This cross-cultural secondary analysis aimed to understand how divorce changes the lives and psychological wellbeing of contemporary Palestinian women, how intersecting identities might influence change, and to recommend areas of Palestinian research development for traditionally marginalised groups.

Method: A single-case narrative was developed from a translated transcript, and common themes were compared with quantitative data from a sample of 93 divorced women assessed with a survey designed by local clinicians.

Results: In the single-case narrative, divorce represented freedom from a “prison-like” marriage and a chance for personal development. Half of the broader sample shared experiences of abusive marriages and most anticipated more freedom following divorce. Differences in age, place of residence and educational level were considered.

Conclusions: Divorce can improve the lives of Palestinian women and provide opportunities for wellbeing and personal growth. However, post-divorce experience may vary depending on age, family support, living situation and educational level. Palestinian researchers are encouraged to enrich understanding in this area by developing methodologies relevant to the sociocultural and political context.

Introduction

Sociopolitical context

Approximately 2,900,034 people live in the West Bank and 1,918,221 people live in the Gaza Strip, which together represent the Occupied Palestinian Territories (OPT).

Between 80-99% of people across OPT are Muslim, with the majority identifying as Sunni (Central Intelligence Agency, 2021a/2021b). Whilst recognised by the United Nations, the State of Palestine is denied by Israel, leading to ongoing conflict. In this context, Palestinian Citizens of Israel (PCIs) have been subjected to human rights violations including forced eviction, arbitrary arrests, and gender-based violence (Amnesty International, 2019). This backdrop of national insecurity and marginalisation is paralleled by the dynamic daily lives, experiences, feelings and concerns of people living in OPT.

A feminist analysis of Palestinian women's narratives suggests that they face both in-group and out-group cultural, political, religious, familial, patriarchal and personal issues in their daily lives whilst living through intractable conflict (Arnd-Linder et al., 2018). Their stories highlight multiple challenges alongside great strength to persist and create a sense of security. This exemplifies the need to develop ways of hearing the voices of traditionally marginalised groups and to understand their experiences, contributing to more empowering narratives and support structures.

Marriage and Divorce

Palestinian women tend to marry at a younger age than men. In 2018, there were 43,515 marriages (United Nations, 2020a). 33% of girls and women married for the first time were aged 18 or under, 62% of women were aged between 19 and 29 years, and 5% were 30 or over. In contrast, 2% of boys and men were aged 18 or under, 87% of men were aged between 19 and 29 years, and 11% were 30 or over (United Nations, 2020b). This discrepancy may reflect societal gender norms in which women tend to inhabit the role of a wife before other forms of occupation, while elder men traditionally occupy a patriarchal role.

However, Palestinian couples are increasingly seeking divorce. In 2018, there were 8,509 divorces in Palestine, compared with 5,009 in 2008 (United Nations, 2020c). This is likely an underestimate, because most divorces in OPT are not processed in civil court, but under religious (Shari'a) law (Cohen et al., 2007). Women are generally discouraged from seeking divorce unless in extreme circumstances, putting the needs of their husbands and children before their own (Meler, 2013).

Reasons for Divorce

There is scant published data on reasons for divorce in OPT. One study explored reasons for divorce based on interview data from 16 female PCIs (Meler, 2013). The researcher described difficulties recruiting women, with some directly refusing to be interviewed and others initially agreeing then avoiding by other means. Interviews were conducted in Hebrew, the participants' second language, acknowledged to potentially limit meaning-making. The researcher found that women's descriptions of life before

and after divorce reflected differences in their social circumstances, which led to the development of three comparative typologies:

- ‘Restricted’ women were described as less privileged in terms of education, occupation, place of residence and socioeconomic status, and were subject to close post-divorce familial supervision.
- ‘Conditioned’ women were reported to earn a reasonable income, had higher educational backgrounds and were able to socialise and work more freely than ‘restricted’ women, yet experienced moderate familial supervision.
- ‘Cosmopolitan’ women were academically qualified, held professional jobs enabling financial independence and were minimally supervised.

A common reason for divorce among women across typologies was experiencing physical violence during marriage. Survivors described a lack of support from their husband’s families, leading restricted lives based on the will of their husbands and living in prolonged fear. However, there were many differences between the three groups. Some women, particularly within the ‘conditioned’ typology, noted the lack of privacy and autonomy within marriage due to the involvement of extended family in their affairs. Meler suggested that this experience may be related to the cultural norm of wives entering into their husband’s collective family rather than the couple forming a distinct family of their own.

Some women within the 'cosmopolitan' typology reported their husband's infidelity as a reason for divorce. Meler suggested that this was in contrast to a broadly accepted culture of polygamy, and that 'cosmopolitan' women may perceive infidelity as a form of gender inequality. They also referred to a mismatch between themselves and their husbands as a reason for divorce. Increasingly, women are better qualified and occupy more senior roles than their husbands, which contravenes traditional gender roles in Palestinian society. Meler proposed that women who have had the opportunity to learn and be exposed to different cultural contexts may seek greater equality and partnership in their marriage, which may conflict with their husband's perceptions and wishes.

Similarities and differences among divorced PCIs provide an initial guide to considering the role of social circumstances in shaping experiences of marriage and divorce among women living in OPT. In line with Intersectionality Theory (Crenshaw, 1991), sexism within Palestinian society may intersect with divorcée status to oppress divorced women. The extent of this oppression may depend on other intersecting aspects of identity such as educational background, place of residence and financial wealth. These varying levels of oppression may impact on psychological outcomes for divorced women in OPT, and on whether, how and from whom they seek support.

Psychological Outcomes of Divorce

There is a paucity of research on psychological outcomes and coping following divorce in OPT. Cohen and Savaya (1997) interviewed nine divorced female PCIs, who reported relying on internal coping resources, such as inner strength and religious faith, rather than reaching out to others or formal supports. The authors associated this with

social norms of accessing support from family, friends and clergy rather than discussing private affairs with professionals. However, families were largely described as unsupportive and refused to help divorced women if and when they did reach out, until after the divorce process was finalised and a minority returned home and were financially supported. Participants described a societal and internalised perception that they were “broken glass” (p.8) which could not be mended post-divorce. They described focusing on practical activities of housework and childcare, putting their personal needs aside in the public sphere.

This study was conducted 23 years ago, and in the intervening time opportunities for PCIs have changed, with more women accessing education and work, and increasing numbers of single-mother families (Meler, 2013). However, the way in which this is realised may differ depending on the resources available to women. Furthermore, it is difficult to determine how transferable these findings are to divorced women in OPT.

Limitations of Existing Literature

A dearth of research explores the experiences of divorced women living in OPT. Given this group may be multiply marginalised – as women, divorcées, and various intersecting identities – the limited evidence base precludes understanding of psychological outcomes and support needs among divorced women from various social backgrounds. Research involving PCIs provides a helpful starting point in understanding the experiences of divorced women living in OPT, but more data is required to address issues of transferability and ensure that this traditionally marginalised group is represented within a developing evidence base.

Aims

The present study aims to build on existing research involving PCIs by analysing mixed method data from divorced women in OPT collected by Palestinian researchers.

Analysis was guided by the following questions:

1. How does divorce change the lives and wellbeing of contemporary Palestinian women?
2. How might intersecting identities influence the impact of these changes?
3. How can Palestinian researchers be supported to develop approaches for collecting, analysing and applying data from traditionally marginalised groups?

Method

Design

This mixed-method study was a cross-cultural secondary analysis of data originally collected in OPT by the Guidance and Training Centre for the Child and Family (GTC) for a project entitled 'My Family is Changing'. A narrative approach was used to analyse a single interview transcript and develop a rich story of one divorced woman, then her experiences were contextualised in quantitative data from a broader survey sample to understand similarities and differences. Consideration was given to the process of analysis in line with the aim of supporting Palestinian research development.

Ethics

At the original point of data collection, the research purpose and voluntary participation was explained, and informed consent was obtained. Ethical approval was granted for secondary analysis by the Institutional Review Board at An Najah University (Appendix 2.2, p.111), and by the College of Medical, Veterinary and Life Sciences at the University of Glasgow (Appendix 2.3, p.112). All data were provided by GTC in fully anonymised form. Quantitative data was coded, and a randomly selected interview transcript was translated from Arabic to English, by GTC in Palestine, so no raw data was transferred or handled locally.

Participants

An inclusive sampling strategy was selected given the ‘hard-to-reach’ nature of a population whose intersecting identities are multiply marginalised (Shaghagi et al., 2011). GTC recruited self-identified divorced Palestinian women from three sources:

1. Via individual or group therapy engagement within GTC.
2. Via non-governmental organisations (NGOs) in Bethlehem and Hebron Governorates, by contacting legal institutions working with women and Ministry of Social Development beneficiaries.
3. Via field volunteers in Dheisheh refugee camp in Bethlehem.

Procedures

Quantitative. Participants were asked to complete a structured survey (Appendix 2.4, pp.113-120), with questions based on GTC clinicians’ experiences of supporting

divorced women, including: demographics, marital roles and responsibilities, relationship quality, reasons for divorce, support during the divorce process, and post-divorce experience. Participants completed additional psychometric measures which were excluded from this analysis. Primary analysis of quantitative data has been conducted for conference purposes but remains unpublished.

Qualitative. Participants recruited within GTC were invited to participate in a semi-structured interview with a female Psychologist (see Appendix 2.5, pp.121-123, for topic guide). Eight women participated in an individual 60-to-90-minute interview. Interviews were audio-recorded and transcribed by a female research assistant. Data could not be obtained for remaining interviews due to the prohibitive cost of translating multiple transcripts from Arabic to English.

Analysis

Narrative analysis was applied to one translated interview transcript (Appendix 0.2.2, p.99). Firstly, to ‘re-story the transcript’ (Nasheeda et al., 2019), the process of characterisation and plotting was done by reorganising the data using narrative-forming questions. Secondly, an analysis of the surface and latent content of the data was developed, whilst noting discrepancies and areas of uncertainty, with the aim of developing a coherent and cohesive narrative (Sharp et al., 2019). A holistic-content approach was used, considering the participant’s story within the wider context of her life (Lieblich et al., 1998, cited in Earthy & Cronin, 2008). This was an iterative process between the original data and the emerging narrative to develop a deeper understanding of how the participant’s life had changed as a consequence of divorce

(Sharp et al., 2019). Polkinghorne's (1995) criteria for meaningful and credible narrative analysis were used to guide development of the narrative (Appendix 2.6, p.124).

Analysis then shifted to exploring shared and divergent elements between the interviewee's narrative and the quantitative data representing the broader sample of divorced Palestinian women (Appendix 0.2.3, p.100). This process was guided by the research questions and explored using techniques from a paradigmatic analysis of narratives to consider similarities, differences and contextual factors (Sharp et al., 2019). Demographic data from the broader sample were considered alongside the interviewee's circumstances to explore social similarities and differences.

Epistemology

A social constructionist epistemological stance was adopted to account for the multiple layers of interpretation between the original participant experience and the final analysed account (Burr, 2015). According to social constructionism, the participant, original interviewer, scribe, translator, and analyst each contributed to the construction of knowledge within this research process. Perspectives and experiences are intersubjectively reconstructed and different members within this process have greater or lesser power to determine the knowledge produced (Thomas et al., 2009). Therefore, the researcher's reading of and engagement with the transcript was considered together with relevant literature and available information about the Palestinian sociocultural context, as well as the researcher's own frame of Western psychological theory, to develop a socially constructed analysis.

Reflexivity

The narrative was constructed in the researcher's voice, illustrated by selected excerpts from the translated participant interview. This process is therefore influenced by the researcher's own experiences, values, and perspectives (Polkinghorne, 1995). There is further risk of bias given the differences in religious, cultural, and social contexts between data collection and analysis, without the opportunity to co-create narratives. As a white woman residing in a Western sociocultural context, positioned as a feminist who believes all women should have the right to divorce regardless of circumstances, the researcher acknowledged the risk of imposing a colonial perspective on the narratives of divorced Palestinian women. In recognition of these power dynamics, a reflective diary and supervision was used to ensure social, cultural, and personal biases arising throughout the analytical process were acknowledged and reflected upon.

Findings

Munira (pseudonym) is a 19/20-year-old divorced woman living in Palestine with her family of origin. Munira married at 15, she was married for three years before seeking divorce, had two children (aged two and three years) during her marriage and was divorced for one year and four months when interviewed. A condensed version of Munira's narrative is presented here with a single direct quote to illustrate each turning point in the story (see Appendix 2.7, pp.125-137 for all source quotes). This narrative was analysed for overarching themes and synthesised with data from the broader survey sample in line with research aims, the outcomes of which are subsequently presented.

Munira's narrative

"Marriage resembles stability, security, love. [...] it means everything. These are the things that I didn't have." (10-15). The mismatch between Munira's expectations of marriage and her experience of it became apparent early in the relationship. Munira indicated that her engagement period was brief and that she and her husband had little time to get to know each other before their wedding. She believed that marriage should represent a loving partnership between equals who can communicate openly and resolve any conflicts together as a couple, rather than relying on family intervention. Munira described her husband as feeling differently about the role of his family in their marital affairs and the nature of communication between a married couple. She noted that her husband's family lived in the marital home and described feeling that the lack of private communication with her husband divided them as a couple and eventually contributed to their divorce.

"...I was living in a prison in this marriage." (144-145). Munira described quickly feeling trapped in a difficult and abusive marriage, filled with chores and obligations, becoming increasingly isolated by her husband and in-laws from her own family. Munira portrayed her husband and in-laws as holding traditionally gendered views of a wife's role in marriage. She reported being assigned various household chores, such as cleaning and caring for her husband's parents, without flexibility or sharing from her husband, and no opportunity for discussion. Exemplifying this, she described being discharged from hospital the day after giving birth to her son and being expected by her husband to clean up the mess that was left in her absence.

Additionally, Munira said her husband often compared her to others, and he would complain to his parents and in-laws when she did not meet his expectations. She described being disallowed from doing certain things, such as spending money for the household without permission, rendering her financially and practically dependent on her husband. Munira recounted that her family handled conflict differently to her husband's, with her husband shouting and readily engaging in arguments with her. Munira described these incidents as leaving her frozen with fear and resulted in her taking care not to upset her husband.

Munira indicated the impact of their marital difficulties on the wellbeing of their children and her ability to engage with her maternal role. However, Munira's transcript included very little about her children during the time of her marriage, which may suggest she was preoccupied with the various demands made of her and the personal impact of the relationship, leaving little capacity for her to hold the children in mind. She described a process of being isolated from her family by her husband and in-laws which began by her husband limiting how often Munira could visit her parents. She recounted that, in front of her family, he expressed love towards her, but in private he expressed hatred, which left Munira concerned no-one would believe her. Her interview describes that, later, Munira's husband and in-laws explicitly told her to cut herself off from her family and blamed them for the marital difficulties.

"I was living in a state of conflict like being in a whirlpool all the time. I have to end this situation; I am unable to live with him or his parents anymore..." (105-106). The cumulative impact of unreasonable expectations and a lack of support eventually

brought Munira to a crisis point. She described feeling increasingly helpless and alone in her situation with her husband and in-laws, coming to feel hated by them and their interference, and isolated without the support of her parents. Munira described her marriage and living situation as so unbearable that she seriously contemplated ending her life. By this stage, prior to the divorce, she had not spoken to her parents in months due to pressures from her husband and in-laws. She feared her family would not understand or help her as they did not know the full extent of what she was going through and were opposed to divorce, especially when there are children involved.

At the height of her crisis, Munira reached out to her uncle and told him what was happening, expecting to be rejected. However, he came for her, and she left that day with just the clothes she was wearing. Munira recounted that her mother-in-law forced her to leave her children behind, but that she felt she had no other choice and that it would ultimately be better for them as she felt unable to meet their needs. Munira stayed with her uncle while her parents adjusted to the idea of her marital separation. They soon welcomed her back home once they learned the extent of what she had experienced during marriage.

“...the first day of receiving my divorce I was free like a bird...” (147-148). Munira feared that her husband and in-laws would continue to make her life difficult when she left. However, the discrepancy between private and public feelings remained and their contact seemingly ended on the day of divorce. The interview conveyed a sense of great relief for Munira to be free of the marriage. Although, Munira feared escaping one cage

only to be trapped in another by her parents. She anticipated that divorced life would be limited and restrictive, as her experience of married life had been.

Munira described her family's concerns for her prospects as a divorced woman, especially her ability to remarry given she had children. They encouraged her to give an alternative version of events publicly to mitigate this risk and preserve honour.

However, this frustrated Munira as she desired her past suffering, for example in childbirth, to be acknowledged. This discrepancy between private and public versions of reality may have echoed the dynamic with her husband. However, Munira's fears of a restricted life were allayed. Shortly following her divorce, she described surprise that she was supported and trusted by her family. Rather than further restriction, she found freedom to live as she wished.

"I changed a lot after divorce, I became a strong woman." (262). In divorced life, Munira appears to have identified with an alternative narrative of inner strength rather than the apparently dominant narrative of weakness and restriction she expected as a divorcée (McLean & Syed, 2015). Her story contrasts a life once dominated by chores and obligations, becoming filled with activities she personally chose and enjoyed. Munira described accessing university after divorce and commencing work, including as a member of her local government. In the process, she discovered her own skills and abilities, and was recognised by others for these, which brought happiness and a sense of excitement. Munira appeared to be developing her sense of identity – what she likes, what she is good at, and how she wishes to live. This was supported by her family and by university lecturers, who provided the encouragement, support and guidance needed

to navigate this process. During the divorce period, Munira was unable to see her children for three months, but at the time of interview, Munira noted her children were staying with her once per week and she was reclaiming her maternal role by developing a more secure relationship with them.

“...I advise every woman who experiences domestic violence not to stay silent and to seek help from specific institutions.” (282-3). At interview, Munira was soon to graduate and looked forward to her future life. Reflecting on her experiences as a divorcée and survivor of domestic abuse, Munira advises others to get to know their prospective spouse before committing to marriage, and to seek help in the face of abuse, to prevent others from experiencing what she did.

Themes for mixed method analysis

Various themes identified within Munira’s narrative could have been explored further using quantitative data from survey respondents (N = 93) (Appendix 2.8, p.138).

Instead, three focal areas were selected to address the aims and scope of the present study. Ratios are reported and reflect variations in the total number of respondents for each question related to missing data.

Domestic abuse during marriage. The domestic abuse, both physical and psychological, described by Munira was also reflected in the quantitative data. Just under half of respondents stated that their husbands were often or always physically violent (N = 39/88), whilst over half were often or always emotionally abusive (N =

52/88) and emotionally neglectful (N = 52/88). Over half of respondents stated that their husband was often or always controlling (N = 53/87) and half stated that their husband was often critical (N = 46/93). This suggests that various forms of domestic abuse were characteristic of approximately half of the marriages within the surveyed sample, sharing some aspects of Munira's experiences.

Family support. Although her family had been cut off from Munira in the last months of her marriage, she reached out to her uncle who supported her in leaving her husband. Under half of respondents reported seeking support from their families "during the period of finalising the divorce" (N = 42/93). Of those respondents, three-quarters reported seeking "psychological support" from family (N = 33/42), whilst just over one-third sought "legal support" (N = 17/42) and support from family to "try and fix the argument" (N = 17/42). Quality of support in each of these domains was rated on a five-point scale from a strong negative ('Bad') to strong positive ('Excellent'). Half of the subset of respondents reporting "psychological support" from family rated it as 'Very Good' or 'Excellent' (N = 17/33). Half of the subset rated "legal support" and support to "try and fix the argument" as 'Very Good' or 'Excellent' (N = 9/17). This suggests that many women were reluctant to approach family for support around divorce, and when they did, it was not experienced as particularly helpful by many. However, respondents were more likely to seek support from family than either "organisations or specialists" (N = 16/93) or "religious representatives" (N = 12/93).

Following a short adjustment period, Munira reported her parents took her in and stood by her decision to divorce her husband. She described living with her family as a

divorcée whilst studying and working, suggesting a degree of financial independence. Over half of respondents reported that they ‘Agreed’ or ‘Strongly Agreed’ with the statement “I feel that my family does not support me nor my decisions” (N = 52/89). Two-thirds of respondents reported their current living situation as ‘Independent’ (N = 59/93), which suggests that they may not live with family members, or that they can move freely, but the definition of this may vary depending on the familial and cultural context of each woman. Just under half of respondents reported that they ‘Disagreed’ or ‘Strongly Disagreed’ with the statement “I think that my financial situation depends on help that comes from my parents or relatives” (N = 38/88). These findings suggest that Munira’s experiences of being supported by family in divorced life are shared by some of the surveyed sample, but her experience of being supported and living with family whilst maintaining financial independence may not be representative of the majority.

Perceptions of freedom versus restriction. Prior to divorce, Munira anticipated a restricted life as a divorcée. However, although Munira lived with her family, she described freedom to socialise and support to take up work and educational opportunities. Three-quarters of survey respondents reported that they ‘Agreed’ or ‘Strongly Agreed’ with the statement “I feel that I will have the freedom to make my own decisions” (N = 70/91) and more than two-thirds with the statement “I feel that I will be able to behave and act freely” (N = 66/91). Over half reported that they ‘Agreed’ or ‘Strongly Agreed’ with the statement “I thought that after divorce I will have more freedom” (N = 53/88) and “I think that I have more freedom and independency after divorce” (N = 56/89). However, over half reported that they ‘Agreed’ or ‘Strongly Agreed’ with the statement “I feel that society monitors my social relationships” (N = 50/90). These data suggest that many women perceive

divorce as providing freedom and independence in some respects, as well as a degree of surveillance within their communities. It is difficult to ascertain how these perceptions translate to women's lives on a more practical level, for example whether women live under familial supervision, have limited relationships and are required to report to their fathers as Munira anticipated. It is also unclear from the available data to what extent women work or study, or engage in social opportunities, as Munira reported.

Intersectional identities

To expand the analysis of similarities and differences in outcomes of divorce between Munira's narrative and the broader survey sample, demographic data were considered in line with Intersectionality Theory (Crenshaw, 1991). Marrying at 15, Munira would have been around 18 years old when she divorced and aged 19-20 at interview.

Munira's narrative suggested that she lived in a relatively urban area, worked in local government and was accessing university education. Corresponding demographic data from the survey respondents were limited but information was available on age when married, age when surveyed, place of residence and educational background. Data on participants' occupations in divorced life were not available. Median ages are presented as data distribution was skewed.

Age when married. Over one-quarter of participants (N = 19/68; Mdn = 20; IQR = 18-24) reported being aged 13-18 years when they married, within the range and similar adolescent developmental stage as Munira. Just under half of participants reported being aged 19-25 years at marriage (N = 29/68), with a minority over 25 years old (N = 11/68). A quarter declined to report age (N = 25/93), the reason for which is unclear.

Age when surveyed. Three-quarters of respondents reported being aged 20-40 (N = 62/80) at the point of survey (Mdn = 33; IQR = 27-40). A quarter were aged 41 and over (N = 19/80), and a minority declined to report (N = 13/80). However, as over half of respondents had been divorced for more than three years (N = 38/66), it is difficult to determine how old they were at the point of divorce in relation to Munira, and how this might have influenced their experiences.

Place of residence. Around one-third of respondents reported living in a village (N = 32/93) and under one-third lived in a refugee camp (N = 26/93), whereas just over one-third lived in a city (N = 35/93). Whilst Munira had access to a university and could work in her local government, it is likely that divorced women living in villages or camps will not have equal access to these resources and privileges.

Educational background. Munira was soon to graduate from university, although it is unclear whether she will join one-quarter of participants educated to diploma level (N = 19/82) or one-fifth at bachelor's level (N = 16/82). One-third of respondents reported completing secondary education (N = 28/82) whilst one-quarter did not (N = 19/82). A minority declined to report their educational background (N = 11/82). Variations in education may influence opportunities and ability to live independently as divorcées.

Developing Palestinian research capacity

Challenges of working with translated cross-cultural data were apparent, including lack of clarity around how concepts such as 'independence' or 'psychological support'

translated across contexts. The Western context is largely informed by individualism, the belief that citizens are independent, self-contained and free to carve out a life of their own, which has been acknowledged to form the majority of psychological research evidence (Henrich et al., 2010). These principles may have influenced the selection of data collection methods in the original study including a mixture of survey questions developed by GTC, self-report measures validated in Western contexts and translated from English into Arabic, and semi-structured individual interviews.

However, the Palestinian sociocultural context is more collectivist, with family life found to be central to many Palestinian adults' wellbeing (Spellings, 2014). The narrative developed from secondary analysis was one of independence enabled by family, who supported the interviewee to live as she wished. However, it also suggested that her family's beliefs differed from that of her husband's. Data collection methods developed and validated in OPT, incorporating family systems, could be helpful to capture concepts of wellbeing and autonomy, and to develop a culturally sensitive picture of divorced women or people with other traditionally marginalised identities within their family contexts.

Another issue which arose was the experience of domestic abuse within the narrative, which appeared to be condoned by the family-in-law and appeared to relate to their investment in traditional gender roles and marital relationships. Although this differed in the participant's family, it is unclear which of these gendered belief systems is more prevalent in contemporary Palestinian society. Consideration of the dominant sociopolitical narrative towards women in addition to individual family narratives merits consideration when developing Palestinian research methodologies, given the

political and structural forms of sexism which will have a bearing on the lives and wellbeing of divorced women (Crenshaw, 1991).

Discussion

A single case narrative ('Munira') told the story of divorced life as representing freedom from the obligation and isolation of an abusive, prison-like marriage which shattered previously held expectations of an equal partnership. Following a crisis period which culminated in divorce and fears of a restricted life with her own family, the interviewee instead described a process of significant personal freedom, connection and growth, which contributed to a greater sense of wellbeing. These outcomes were facilitated by supportive relationships, including within her family, and were shaped by opportunities to access work and higher education. When compared with findings from the broader surveyed sample, similarities and differences became apparent, suggesting that the interviewee's experiences were not representative of the majority. Further comparison was done in relation to intersectional identities, and reflections were used to consider means of developing research capacity in Palestine. Findings are discussed in the context of existing literature and the strengths and limitations of this study.

Contemporary divorced Palestinian women

Divorce was portrayed as changing Munira's life for the better, representing freedom, greater autonomy, inner strength and the opportunity to reconnect with personal values regarding work, study, personal interests, family and motherhood. Survey respondents

largely anticipated more freedom and independence following divorce, although it was difficult to assess with the available data whether these expectations were met. These findings contrast earlier literature, in which divorced female PCIs engaged in domestic duties to hide themselves from the stigma of public view (Cohen and Savaya, 1997).

Munira's narrative indicates that reasons for divorce among women in OPT may be multi-faceted: for example, a lack of privacy and autonomy within her relationship, strict gender roles, incompatibility with her husband, lack of spousal support, and domestic abuse. Experiences of physical violence during marriage were shared by just under half of all survey respondents, whilst over half experienced emotional abuse. These findings are consistent with previous research on reasons for divorce among PCIs, in which domestic abuse was a reason among women across social strata, incompatibility was a reason among more highly educated and financially independent women, and a lack of autonomy was a reason among moderately educated women and partially independent women (Meler, 2013).

Munira reported a brief engagement period, which prevented the couple from getting to know one another before marriage and may have limited assessment of compatibility. A study involving PCIs noted that prior to signing a marital contract in the eyes of religious and civil law, couples are prevented from getting to know one another due to religious gender segregation customs. Some couples familiarise themselves in the period in-between signing their marital contract and living together to commence married life, during which they can instigate 'contract divorce'. The most common reason for dissolution of marriage was couples lacking compatibility and women

disliking aspects of their husband's personality and behaviour (Cohen & Savaya, 2003). Had Munira had the opportunity to do this, then it may have prevented her from feeling trapped in a marriage she likened to a prison. Additionally, Munira recounted distress in response to the discrepancy between her husband's public and private behaviour. This experience sounds similar to the concept of 'gaslighting' developed in Western psychology, in which women can be made to feel that their perception of reality is false as a form of emotional control (Stern, 2007). However, this may have been a method of preserving family honour and status in the Palestinian context (Ruggi, 1998).

Munira benefited from the support of her family following divorce, who facilitated her freedom and independence to engage in a broader range of activities. However, in the process of domestic abuse, she became isolated from her family and was uncertain as to whether divorce would lead to a more restricted life with them, perhaps influenced by social norms (Meler, 2013). She only reached out to her uncle when she reached crisis point and was contemplating suicide. Evidence suggests that social isolation is a strong driver in suicidality among Palestinian women (Dabbagh, 2012), which is consistent with Munira's feelings of entrapment and loneliness in marriage.

Very few survey respondents reported seeking professional support during divorce, which may relate to perceptions of stigma around women seeking divorce in Palestinian society (Cohen and Savaya, 1997). Just under half reported seeking family support during the divorce process, and family support was not deemed to be helpful by many, but following divorce, over half believed that their family stood by them and their decisions. Two-thirds of respondents reported living 'independently' and just under half

reported being financially dependent on family, but the quality of family relationships is unclear. Previous findings suggest that Palestinian women may have complicated family relationships following divorce, due to concerns about honour (Ruggi, 2005).

The Impact of Intersecting Identities

Although a full intersectional analysis was not possible with limited available data, age, place of residence and education were compared. Munira married at 15, and over one-quarter of participants also reported being aged 13-18 at the point of marriage. During this adolescent developmental stage, young women may be in the process of developing their own personality and interests (Erikson, 1950). A contemporary framework proposes that identity development should be considered in the individual's sociocultural context (McLean & Syed, 2015). This framework attends to how an individual's personal narrative intersects with the societal 'master narrative' and the 'alternative narratives' they may identify with and have been exposed to within their family and community. It seems that Munira's family and educational background may have provided alternative narratives to the ones influencing her husband's belief systems. This contradiction between actual and demanded identity was recounted as distressing and could only be resolved following divorce when Munira had the opportunity to develop more personally valued identities, for example as a student.

Following divorce, Munira attended university to study and worked as a member of local government, she lived in a relatively urban area and divorced at a young age. A majority of divorced women lived in villages or refugee camps, where they are unlikely to have access to the same resources and privileges as Munira. One-third of survey

participants reported completing secondary education whilst one-quarter had not reached that level. This lack of education would limit opportunities to access university study and higher-paid employment. Post-secondary education has been found to be significant in the lives of single Palestinian women, in some cases determining prospects of future marriage and opportunities for autonomy (Johnson, 2010). However, analysis was limited as post-divorce occupations were not measured.

Nonetheless, requirements to hold these intersecting and contradictory identities may serve to further oppress divorced women in OPT, increasing distress and restricting support options. This is consistent with Intersectionality Theory (Crenshaw, 1991), and previous findings involving PCIs which show variations in familial supervision and independent living based on social status (Meler, 2013). Whilst Munira may be described as a 'Cosmopolitan' woman in the context of her circumstances, many other women may be more 'Restricted' or 'Conditioned' depending on where they live and the belief systems of their families, altering their autonomy and access to opportunities. Interestingly, Munira and her family are described as holding different beliefs to her husband and in-laws about gender roles and marriage, which suggests that these factors may vary widely among families even within relatively similar social circumstances. Meler (2013) suggested that exposure to Westernised beliefs about marital relationships, such as via higher education, may influence women's expectations of equality and privacy in marriage, which may contravene some social and religious norms, for example for families-in-law to live with married couples.

Developing Palestinian research capacity

Caution is needed to avoid replicating some of the failings identified in the Global Mental Health movement (Wainberg et al., 2017). It has, in some cases, been argued to be motivated by colonial imperialism, for example by importing Western evidence-based solutions to cross-cultural problems without consideration of or respect for local approaches (Whitley, 2015). In the original study, data collection methods were arguably influenced by Westernised, individualistic approaches to measuring and understanding experiences. However, analysis suggested the important role of family systems in the lives of Palestinian women, including their experiences and access to opportunities following divorce. Incorporating family systems in methodological development and data collection could be helpful for future research in Palestine with marginalised groups, to ensure findings are relevant and applicable in context.

Furthermore, analysis suggested that there may be different, sometimes contradictory, narratives at play in the lives of divorced women, including within themselves, their families, their communities and the wider sociopolitical context within which they live. These different systems may influence the lives of women and other traditionally marginalised identities within OPT (McLean & Syed, 2015). Developing theories, models and methods congruent with the influence of these belief systems on the lives of traditionally marginalised groups within OPT could enable a deeper level of analysis in relation to mental health and wellbeing. Finally, given marginalised identities are under-represented as both participants and researchers, involving experts by experience and peer researchers in future Palestinian research could ensure that recruitment and data collection methods are appropriate and relevant to the population, and could improve quality of data (e.g., Buffel, 2019).

Strengths and Limitations

This study provides an initial contribution to understanding the experiences of divorced women in OPT and suggests considerations for Palestinian researchers to develop further understanding of people with traditionally marginalised identities. Although only one translated transcript was available, an in-depth narrative analysis of a single case provided rich information on one Palestinian woman's experience of divorce and facilitated mixed-method comparison with available data. Unfortunately, it was not possible to co-create this narrative through member checks and follow-up interviews due to the nature of secondary analysis (Nasheeda et al., 2019), which may limit the narrative's credibility. Whilst domestic abuse was experienced by the interview participant and many survey respondents, consequences regarding psychological trauma were not measured to enable analysis.

Furthermore, interpretations were based on Western psychological theory, the dominant framework underpinning the researcher's understanding of human behaviour and motivation. However, attempts were made to contextualise these interpretations in the sociocultural frame of participants using principles of reflexivity during the iterative analytic process, which is consistent with the social constructionist epistemological stance (Burr, 2015). This study aimed to identify areas for Palestinian researchers to develop understanding in this area, rather than to draw any definitive conclusions about the experiences of women in OPT from a distance.

Clinical Implications and Research Recommendations

Divorce has been demonstrated to represent positive change in the lives of many Palestinian women, although access to opportunities depend on their social and familial circumstances. It is helpful for clinicians to be aware of these variations, and to assess not only at an individual level but also consider systemic factors influencing the lives of divorced women. Future research could involve interviews with families, individually or collectively, to understand beliefs and perceptions towards marriage and divorce.

This analysis identified that many divorced women in OPT had survived domestic abuse. Research based on theories, models and methods tailored to the Palestinian context could explore consequences in relation to psychological trauma, to further develop understanding of mental health and wellbeing of this population. This could involve a critical realist stance to consider sociopolitical factors, such as legislation and policies, that affect the lives of divorced women (Danermark et al., 2019), as well as an intersectional analysis of differences within the population of Palestinian divorced women to consider variations in opportunities and disadvantage which may influence outcomes (Christensen & Jensen, 2012). Involving divorced Palestinian women in the process of design, recruitment, data collection and analysis may help to ensure the credibility and relevance of this future research.

Women were more likely to seek help from family than from professionals, although given variations in family belief systems and narratives this might sometimes be more harmful than helpful to women's wellbeing. Shame and concealment could play a role in relation to preserving family honour in the Palestinian sociocultural context,

therefore a safe, non-judgemental therapeutic space for women to share their experiences would be important within services. It could be helpful to consider strategies to make services more accessible to women in these circumstances, for example by providing information in a variety of formats and promoting services in a variety of settings, including clarity around confidentiality to ensure women feel safe to seek help. Research and evaluation of these approaches could support accessibility.

Conclusions

This secondary analysis explored how divorce changes the lives and wellbeing of contemporary Palestinian women, and how intersecting identities may influence the impact of these changes, with the aim of suggesting methods and focal points for future research. These findings demonstrate that divorce can improve the lived experience of Palestinian women, representing freedom from domestic abuse and opportunities for personal development, thereby countering the dominant narrative that divorce leads to ostracism, stigma and lack of opportunity. However, divorced women may have very different experiences depending on personal and social characteristics such as age, family support, living situation and educational background. Palestinian researchers are well-placed to continue advancing understanding in this area and are encouraged to do so by developing methodologies relevant to OPT sociocultural and political contexts, in equal partnership with, rather than secondary to the methods of, Western researchers.

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Appendix 0.1: Original Project Proposal

Final MRP Proposal

Why are older people living in areas of deprivation under-represented in psychological therapy services? A Critical Realist Framework Analysis grounded in older people's perspectives.

Submission Date: 16th December 2019

Abstract

Background: Older people, aged 65 years or over, are under-represented in psychological therapy services compared to younger adults. Existing evidence highlights individual and systemic barriers to access. However, the perspectives of older people living in areas of deprivation have not yet been sought. An existing conceptual framework of access to healthcare (Levesque et al., 2013) may provide a theoretical explanation for the interaction between individual and systemic barriers but has yet to be applied in a related context.

Aims: To build on existing research by developing an understanding of the factors influencing access to psychological therapy services from the perspectives of older people living in deprived areas, to determine whether Levesque and colleagues' framework can help to explain these factors, and to integrate perspectives and theory into a unified explanation.

Methods: A qualitative design will be employed. Approximately 10 to 16 people aged over 65 years and living in the most deprived quintiles of the Scottish Index of Multiple Deprivation will be recruited via community organisations for semi-structured interviews. Data will be considered within Levesque and colleagues' framework using Framework Analysis methodology.

Applications: Findings could contribute to the development of targeted quality improvement interventions which could be tested in future research. They will be disseminated to participants, participating community organisations and local services.

Introduction

Evidence suggests that older people referred for psychological therapies are more likely to complete and achieve reliable clinical improvement than younger adults (Pettit et al., 2017). However, they are less likely to be referred and more likely to be prescribed medication (Walters et al., 2018). Therefore, older people continue to be under-represented in psychological therapy services.

Factors influencing access

The Older People's Psychological Therapies Working Group outlined various barriers limiting access to services, including: practical issues, such as reduced mobility and limited access to transport; negative stereotypical views held by key stakeholders regarding the benefit of psychological therapies; and a lack of appropriate and available psychological therapy services for older people (Toner, 2011, pg. 8). These factors have been explored in existing research at the individual level, from the perspectives of older people, and at the systemic level, from the perspectives of General Practitioners (GPs) and healthcare professionals (HCPs).

Individual factors

Many older people hold positive views of psychological therapies, but some report being unfamiliar with the term and prefer 'counselling' (Hannaford et al., 2019). Some believe that mental health difficulties are untreatable as they view them as an inevitable consequence of ageing. Older people may be more likely to rely on their GP to identify mental health needs and refer to appropriate services in the context of a lack of information about available services and systemic stigma (Overend et al., 2015; Stark et al., 2018). Therefore, it appears that although

there are some individual barriers to representation of older people in psychological therapy services, there are potential systemic and structural barriers to access if GPs serve as the main source of information and referral.

Systemic factors

Some GPs report holding stereotypical views of mental health in later life which impact on their decision to refer older people for psychological therapies. Others report concerns about the ability of services to accommodate the needs of or be acceptable to older people, for example due to lengthy waiting lists. Some GPs described a preference to treat older people with medication, referring to social support organisations or by providing supportive counselling during consultations (Collins & Corna, 2018; Overend et al., 2015).

These factors were largely supported by a recent systematic review of HCPs views of managing depression in later life, which additionally highlighted a tendency for HCPs to prioritise physical health needs and medical management in the context of the perceived complexity of older age (Frost et al., 2019). These factors indicate that there are systemic barriers limiting the opportunity for older people to be referred for psychological therapies, particularly if they depend on GPs or other professionals to initiate this process.

These studies have helpfully explored the perspectives of older people, GPs and other HCPs on the individual and systemic barriers to access. However, none have considered these in the context of a specific theoretical framework, which could help to structure understandings of the phenomena and guide practical change. Another limitation is the lack of sampling from deprived areas. This is an important point, given the potential for pre-existing health

inequalities experienced by people in areas of deprivation, compared to those living in more affluent circumstances.

Deprivation in later life

Deprivation has been found to negatively affect the health and wellbeing of older people in many ways. People living in deprived areas were found to develop more than one physical or mental health condition between 10 to 15 years earlier than people living in affluent areas. They are also more likely to experience both mental health and physical health problems (Barnett et al., 2012). Older people from working class backgrounds are more likely to experience anxiety and depression than those from higher social classes but are less likely to seek help (Green & Benzeval, 2011). Additionally, people living in more deprived communities can experience decision-making and social change as being done to them rather than with them, particularly in later life (Garnham, 2018; Scharf, 2005). Therefore, older people living in areas of deprivation may have unique perspectives on access to psychological therapy services, which have not yet been heard.

A conceptual framework

One potential theoretical explanation for the under-representation of older people in psychological therapy services is presented in the conceptual framework of patient-centred access to healthcare (Levesque et al., 2013). A major strength of this framework is that it uniquely outlines the relationships between both individual and systemic factors which can serve to either facilitate or limit access at each stage in the process (see Figure 1).

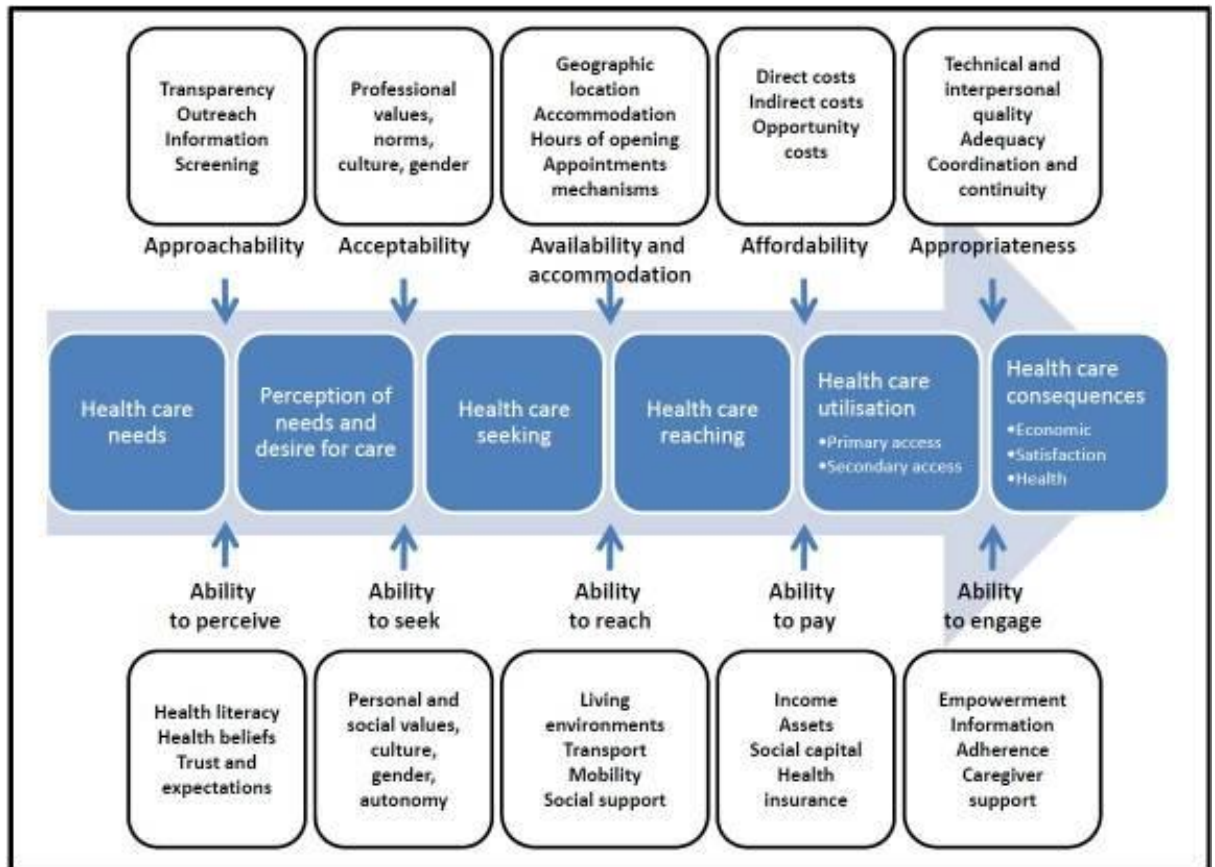


Figure 1: Patient-centred conceptual framework of access to healthcare services (from Levesque et al., 2013; Permission to reproduce this figure has been granted by Creative Commons 2.0 Attribution licence).

The framework was originally developed from a review of Canadian evidence but has since been successfully applied in different sociocultural contexts to develop understandings of individual and systemic factors influencing access to healthcare for marginalised groups. This includes lesbian, gay, bisexual and transgender (LGBT) people in the US (Romanelli & Hudson, 2017) and frail older people in Poland (Kurpas et al., 2018). However, it has not yet been applied within the UK healthcare system nor specifically to mental health care.

Aims & Research Questions

Overall, the proposed project aims to build on existing research by developing an understanding of the individual, systemic and structural mechanisms by which older people living in areas of deprivation are under-represented in psychological therapy services.

Given that existing literature does not include perspectives of individuals living in these circumstances, they will be central to developing this understanding. These perspectives will be contextualised within Levesque and colleagues' (2013) conceptual framework, which at present appears to offer the most comprehensive theoretical explanation of the individual and systemic factors limiting or facilitating access to healthcare.

This study will be guided by the following questions:

- What are the perspectives of older people living in areas of deprivation regarding access to psychological therapy services?
- To what extent can these perspectives be understood within and explained by Levesque et al.'s (2013) conceptual framework?
- Can these findings be integrated into a unified theoretical explanation of the under-representation in psychological therapy services of older people living in areas of deprivation?

Planned Method of Investigation

Participants

People aged 65 years and over living in areas of deprivation will be purposively sampled. ‘GPs in the Deep End’, a project which aims to transform primary care services to meet the needs of the most deprived communities in Scotland, identified that of the 100 GP practices considered to be ‘at the Deep End’, 85 are located in Glasgow (Watt, 2011). These are defined by the Scottish Index of Multiple Deprivation (SIMD), which sorts all postcodes within Scotland from the most to the least deprived. As older people living in deprived communities within Glasgow could be viewed as a representative subset of the target population, this system will be used to guide the sampling strategy. Recruitment will be targeted at postcodes classified within the two most deprived quintiles using the SIMD. Given the potential difficulty of recruiting from this population, it may be necessary to include sampling of adjacent postcodes to include older people living in neighbouring areas.

Inclusion and Exclusion Criteria

Eligibility will be based on participants being aged 65 years or over, being fluent in English and having the capacity to consent to and participate in the interview process. Participants will only be excluded if they are deemed by the researcher to be unable to participate meaningfully in the consent and interview process. This would include drug or alcohol dependence or intoxication, significant cognitive impairment, and sensory impairments which cannot be reasonably compensated for by the use of existing equipment.

Recruitment procedures

Given the purpose of the project, to identify the perspectives of older people who may not have accessed psychological therapy services, recruitment will be sought from the community as opposed to clinical settings. A similar approach has been used to recruit participants via third sector community organisations in previous Framework Analysis research (e.g., Ploetner et al., 2019). To facilitate recruitment, the following sources operating in relevant areas will be approached to act as intermediaries:

- practitioners from a third sector organisation, Community Connectors, which offers person-centred support to socially isolated older people;
- senior staff and housing officers at housing associations and supported accommodation occupied by older residents; and
- community engagement figures within churches and other community organisations.

Intermediaries will be asked to distribute information sheets about the study to all eligible individuals and obtain written informed consent to share contact information and preferences with the researcher. The researcher will then contact all who agree to provide any additional information, obtain initial informed consent for participation, and arrange an interview date, time and venue. This may be done by telephone or by an initial meeting, based on the preferences of each participant. If done by telephone, then written informed consent will be obtained prior to the interview. These steps aim to facilitate participation without posing additional barriers to older people accessing the study, such as an opt-in system.

Design

A qualitative approach informed by Critical Realist epistemology will be employed in response to the above aims and research questions. Critical Realism proposes that it is imperative to hear

and understand the experiences and perspectives of individuals at the empirical level. By doing so, it is possible to gain insight into the underlying structural conditions and mechanisms by which empirical experiences occur and to propose practical means of change (Danermark et al., 2002). Critical Realism acknowledges the filter of lived experience and interpretation as a means of accessing these deeper levels of reality, which is important given that this population is typically excluded from discussions about change in their own communities (Scharf, 2005). It also requires pre-existing theories to be critically examined in light of new data and adapted accordingly, which is compatible with the aim of applying Levesque and colleagues' (2013) framework.

Research Procedures & Data Analysis

Individual semi-structured interviews will be conducted with each participant lasting for around one hour each. Interviews will be audio-recorded and transcribed as soon after each interview as possible to begin the analytical process alongside data collection. Field notes will be kept by the researcher to aid in reflexive analysis.

Framework Analysis methodology (Ritchie & Spencer, 1994) will be applied. This approach is compatible with Critical Realism as it provides a direct and transparent link between the original data at the empirical level and the subsequent conceptual coding and analysis. This ensures that any explanations and understandings are grounded in participants' perspectives. Data management and analysis will be conducted iteratively alongside data collection using the steps outlined by Spencer and colleagues (2014, pp. 282-3). The initial thematic framework will be based on the dimensions of Levesque and colleagues' (2013) conceptual framework but with flexibility to distinguish and incorporate any non-conforming data.

If time allows, credibility of the research could be enhanced by offering participants the opportunity to provide member reflections on the findings, and any additional or alternative data gathered from this could be incorporated into the analysis and write-up (Tracy, 2010).

Sample Size Justification

It is difficult to pre-determine sample size based on this design, which aims for data sufficiency rather than a particular number of interviews completed. Based on previous DClinPsy theses which applied Framework Analysis, it is estimated that individual semi-structured interviews with between 10 to 16 participants may be sufficient (Artis, 2012; Purvis, 2017; Xanidis, 2018). However, the total number of participants will depend on the richness of interview data obtained and concurrent data analysis to ensure sufficient exploration of the topic. This will be reviewed on an ongoing basis throughout data collection and analysis, and in discussion with supervisors, to balance feasibility with data sufficiency.

Settings & Equipment

Where possible, interviews will be arranged at a neutral location convenient to the participant (e.g., the Community Connectors office). Due to stigma associated with mental health settings, hosting interviews within them may pose a barrier to participation, which directly counters the aims of this project. Transportation has been found to be a common barrier to clinical research participation for older people, with home visits maximising participation (Marcantonio et al., 2008). Therefore, if necessary, home visits would be offered to facilitate participation in this study.

A demographic questionnaire will be devised to obtain participants' age, gender, postcode (for SIMD classification), and years of education. Details regarding participants' GP name and practice will also be collected for health and safety purposes. The 10-item Clinical Outcomes in Routine Evaluation (Barkham et al., 2013) measure will be used to characterise the level of psychological distress experienced within the sample.

A semi-structured interview schedule will be developed based on the research questions, relevant literature, Levesque and colleagues' framework, and critical realist epistemology. Given potential concerns about the use of language and terminology in limiting access, these questions will be sent to the Mental Health Network for consultation with their older members to ensure that they are accessible from their perspectives. They will also be sent to Community Connectors Practitioners for consultation. Effort will be made to minimise jargon and use plain English throughout the process.

An audio recorder, microphone and laptop will be used for data collection. Free software, Audacity and Microsoft Word, will be used to manage interview audio and transcription. Microsoft Excel will be used to manage and display data using Framework methodology, based on existing guidelines (Swallow et al., 2003).

Health and Safety Issues

Researcher

If home visits are required, then information would be sought from the intermediary about any known risks regarding the person or their home environment. This would be assessed by the researcher and her supervisors to decide whether a home visit would be appropriate. At each home visit, the intermediary would be asked to personally introduce the researcher to the participant and leave prior to the beginning of the interview to maintain confidentiality.

All interviews would be conducted during working hours. At all times, the researcher would follow local policies related to lone working, including the NHSGGC Lone Working Policy, ensuring that a designated person is aware of her whereabouts, the times that she will be in the participants' home or other setting and plans to leave, and will expect a telephone call at an agreed time to ensure the researcher's safety.

Participants

Any known risks to participants will be identified by discussion with the intermediary prior to their participation and assessed by the researcher and her supervisors. Should risks to the safety of participants or members of the public become apparent during the course of the interview process or any related contact between researcher and participants, then the researcher would contact and inform the participants' GP. Information about the limits of confidentiality will be shared in participant information sheets and reiterated by the researcher both at the first point of contact and during the pre-interview briefing conversation to ensure the participant is giving fully informed consent.

Ethical Issues

Ethical permission will be sought and granted from the MVLS College Ethics Committee as no NHS patients or staff will be recruited for the study. There are potential ethical implications associated with recruiting participants via intermediaries, particularly if they provide the person with support or accommodation. All those approached for recruitment will be informed that participation is voluntary and will be made aware that they can withdraw at any time until the final write-up. The researcher's contact details and those of an independent person will be outlined in the information sheet provided to participants should they have any questions following their interview or wish to withdraw from the study. No information derived from confidential interview content will be shared with any intermediate organisation until it has been anonymised and analysed for reporting and dissemination to protect the identity of individual participants.

Due to the nature of the research question and interview schedule, there is a possibility that discussing mental health difficulties and access to psychological therapies may be distressing to participants, particularly if they do not ordinarily speak about these matters. If this does occur, the researcher will offer the participant a break in the interview and a collaborative decision will be made as to whether or not to continue. The researcher will attempt to support the participant in managing this distress and relevant signposting information would be provided so that participants are not left holding any difficulties they have disclosed without any follow-up support. If the participant remains distressed, then the researcher would seek consent from the participant to contact and inform their GP.

All audio recorded and transcribed information will be stored on a university encrypted laptop. Data will be backed up on an encrypted memory stick and on the University of Glasgow secure network. Paper copies of consent forms will be stored in accordance with General Data Protection Regulations and local guidelines and will be stored in a locked filing cabinet within NHS premises. Only the researcher and academic supervisors will have access to the data in its transcribed form. Any paper files containing personal information used to contact participants (e.g., name, address) will be destroyed by shredding upon the completion of study and any electronic information will be deleted.

Financial Issues

The study will require financial support for stationery costs, but all other equipment will be borrowed at no cost from the Institute of Health and Wellbeing at the University of Glasgow. All costs are detailed in Appendix 2.

Timetable

September 2019	Submit MRP Proposal for blind review
December 2019 – February 2020	Complete and submit University ethics form Processing of ethics – making any corrections as appropriate
February – October 2020	Data collection & analysis Beginning write-up
November – January 2021	Finalising write-up
28th February 2021	Submission of report for examination
April 2021	Viva

Practical Applications

Findings could inform the development of targeted quality improvement interventions which could be applied and tested in future research (Medical Research Council, 2006). Findings will be disseminated as a Plain Language Summary by local organisations to service users, and the full thesis will be made available electronically via the University of Glasgow portal.

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Walters, K., Falcaro, M., Freemantle, N., King, M., & Ben-Shlomo, Y. (2018). Sociodemographic inequalities in the management of depression in adults aged 55 and over: an analysis of English primary care data. *Psychological Medicine*, 48(9), 1504-1513.

Watt, G. (2011). GPs at the Deep End. *British Journal of General Practice*, 61(582), 66-67.

Appendices

1. Health and safety form
2. Equipment cost form

Appendix 1

HEALTH AND SAFETY FOR RESEARCHERS

1. Title of Project	Why are older people living in areas of deprivation under-represented in psychological therapy services? A Critical Realist Framework Analysis grounded in older people's perspectives.
2. Trainee	Jennifer Malik
3. University Supervisor	Dr Naomi White
4. Other Supervisor(s)	Prof Hamish McLeod
5. Local Lead Clinician	Dr Rosie Begbie
6. Participants: (age, group or sub- group, pre- or post-treatment, etc)	<ul style="list-style-type: none"> • Aged 65 and over • Cognitive and sensory capacity to engage in semi-structured interview process • Living in postcode within 30% most deprived areas of Scottish Index of Multiple Deprivation • Recruited from community via third sector intermediary organisations
7. Procedures to be applied (eg, questionnaire, interview, etc)	Demographic questionnaire CORE-10 Semi-structured interview
8. Setting (where will procedures be carried out?) i) General	At neutral locations convenient to participant and researcher e.g. offices of intermediary organisations, where possible.
ii) Are home visits involved	Yes, if necessary, to facilitate participation in the study, given known barriers such as lack of transportation or social capital, which could introduce sampling bias should such participants be excluded.
8. Potential Risk Factors Identified see chart	<ul style="list-style-type: none"> • This population is not normally associated with dangerous or unpredictable behaviour. • It is possible that a semi-structured interview focused on the topic of psychological therapies and both the individual and systemic barriers experienced in accessing them to treat any mental health difficulties may be distressing to participants particularly if they do not ordinarily discuss these matters.

	<ul style="list-style-type: none"> • Should participants be able to attend for interviews at the offices of the intermediary organisation from whom they were recruited, then it would be ensured that those settings would have procedures in place to minimise risk to staff and are thought to be adequate in the context of the proposed study. • If home visits are the only means to facilitate participation, then there may be risks involved in travelling to the participants' home, in the geographical location of the home, and within the home.
<p>10.Actions to minimise risk (refer to 9)</p>	<ul style="list-style-type: none"> • Should participants become distressed or frustrated during the interview process then the researcher would postpone the interview and attempt to provide verbal reassurance and comfort and offer a comfort break. If it is apparent that there is an unmet need then the researcher could signpost the participant to discuss this with their GP. • Should risks to the safety of participants or members of the public become apparent during the course of the interview process or any related contact between researcher and participants, then the researcher would contact and inform the participants' GP. Information about the limits of confidentiality will be shared in participant information sheets and reiterated by the researcher both at the first point of contact and during the pre-interview briefing conversation to ensure the participant is giving fully informed consent. • If home visits are deemed to be required, then any recent risk assessment will be reviewed by the researcher and her supervisors. However, as participants will potentially not be involved with a clinical team or have been seen recently, information on potential risk factors regarding participants and their home environments will be sought from the relevant intermediary organisation(s). Lone working policies for the Health Board will be adhered to and all home visits would be conducted during normal working hours.

Appendix 2

RESEARCH COSTS & EQUIPMENT

RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES

Trainee: Jennifer Malik

Academic Supervisors: Dr Naomi White & Prof Hamish McLeod

Local Lead Clinician: Dr Rosie Begbie

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationery	<ul style="list-style-type: none"> Envelopes A4 – 1 box of 250 to send interview topic guides for consultation, to send transcripts to participants for member reflections, and to send plain language summaries of findings to participants and intermediary organisations Ream of white paper x 3 for transcription and data analysis. 	Box of 250 A4 envelopes = £10.73 3 reams of 500 sheets white paper at £2.57 each = £7.71
Postage	<ul style="list-style-type: none"> Postage to send interview topic guides for consultation (30), to send transcripts to participants for member reflections (20), and to send plain language summaries of findings to participants (20) and intermediary organisations (50) – 2nd class x 120 (100 large letters up to 100g; 20 large letters up to 250g) Freepost x 20 for any written member reflections to be returned to researcher 	100 large letters at £0.83 per 100g = £83 20 large letters at £1.32 per 250g = £26.40 20 freepost envelopes at £0.61 each = £12.20
Photocopying and Laser Printing	<ul style="list-style-type: none"> Participant information sheets (large print) - estimated 4 pages x 50 Consent form (large print) -estimated 2 pages x 20 Demographic questionnaire – 1 page x 20 Interview topic guides - estimated 2 pages x 40 (including for consultation) Field notes record form – estimated 2 pages x 20 CORE-10 paper forms – 1 page x 20 Transcripts – estimated 40 pages (large print) x 20 	1200 pages of B&W print at £0.05 per page = £60
Equipment and Software	<ul style="list-style-type: none"> Audio recording equipment Laptop Encrypted USB stick 	Request to borrow from Department

	<ul style="list-style-type: none"> • Foot pedal for transcription 	
Measures	CORE-10	Available free of charge from CORE IMS under copyright conditions
Miscellaneous	Public transport costs for home visits or participant travel costs, based on single bus ticket costs x 20	10 single journey tickets for £21 x 2 = £42
Total		£242

For any request over £200 please provide further justification for all items that contribute to a high total cost estimate. Please also provide justification if costing for an honorarium:

Cost estimate includes public transport costs to cover home visits for all 20 participants, which may not be necessary depending on ability of participants to attend alternative settings for interview. Single tickets can be purchased on an ad hoc basis.

Appendix 0.2: Author's contribution to secondary project development

- Literature review and familiarisation of Palestinian sociocultural context to inform project development
- Identifying relevant aims and research questions based on available secondary data and extant literature in collaboration with supervisors
- Decision-making around methodological approach and epistemological stance in collaboration with supervisors
- No access to original proposals, previous published work or conference proceedings regarding the primary data collection or analyses
- Screening and cleaning of quantitative data/reviewing of qualitative data and querying areas of uncertainty with the original research team via supervisor (see Appendix 0.2.1, p.TBC)
- Development of mixed method analysis using narrative approach (see Appendix 0.2.2/0.2.3, pp.TBC)
- Narrative analysis of single-case transcript, intrathematic analysis of narrative and decision-making around cross-cutting themes based on available quantitative data
- Descriptive statistical analysis of available quantitative data to further analysis of above themes and intersectional differences
- Reflections on the process independently and in supervision to develop recommendations for future Palestinian research
- Interpretation of the findings
- Write-up of the project

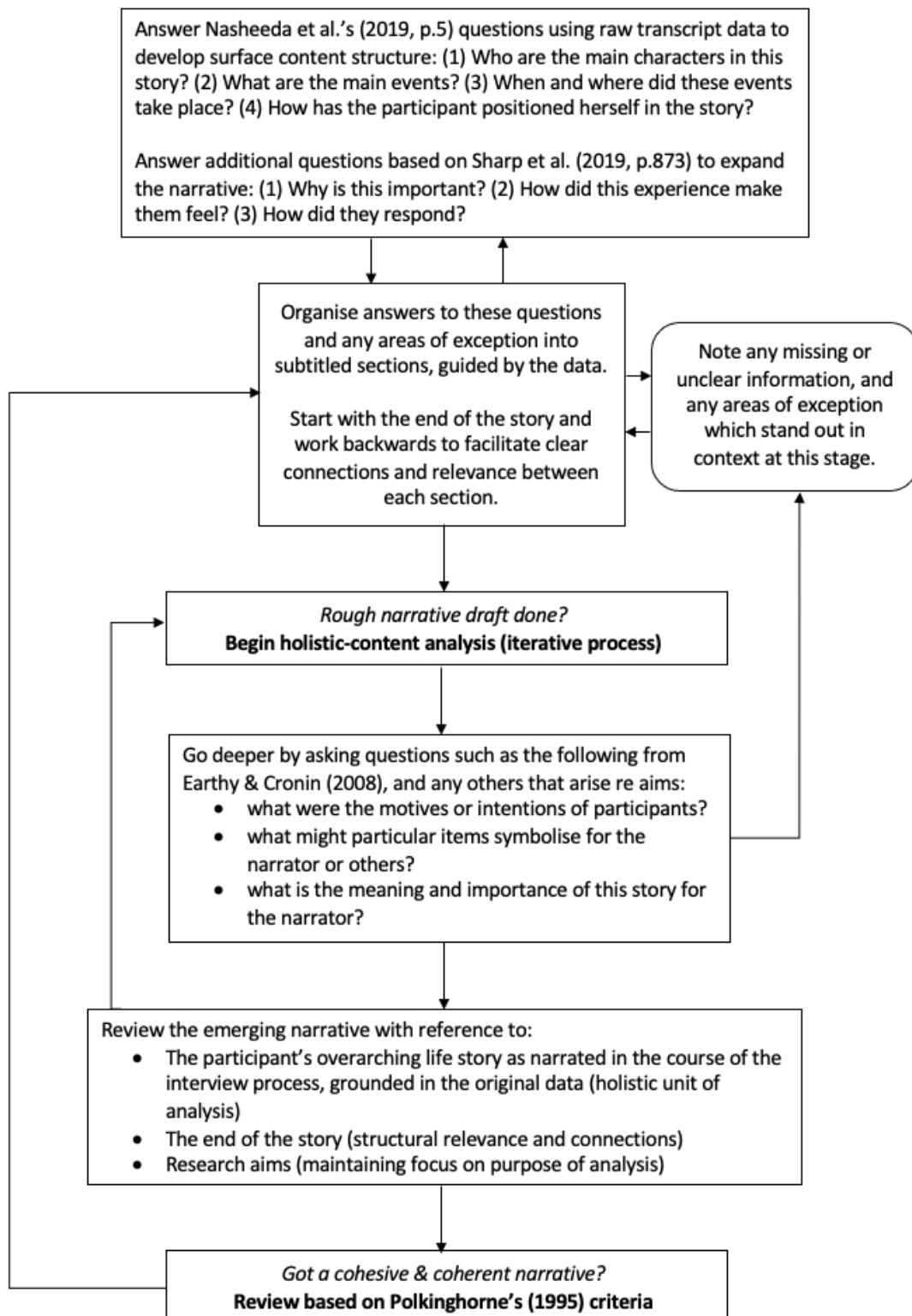
Not done by author:

- Ethical approval obtained from Institutional Review Board at An Najah University/MVLS by supervisor Prof Hamish McLeod
- Liaison with Palestinian research team by Prof Hamish McLeod

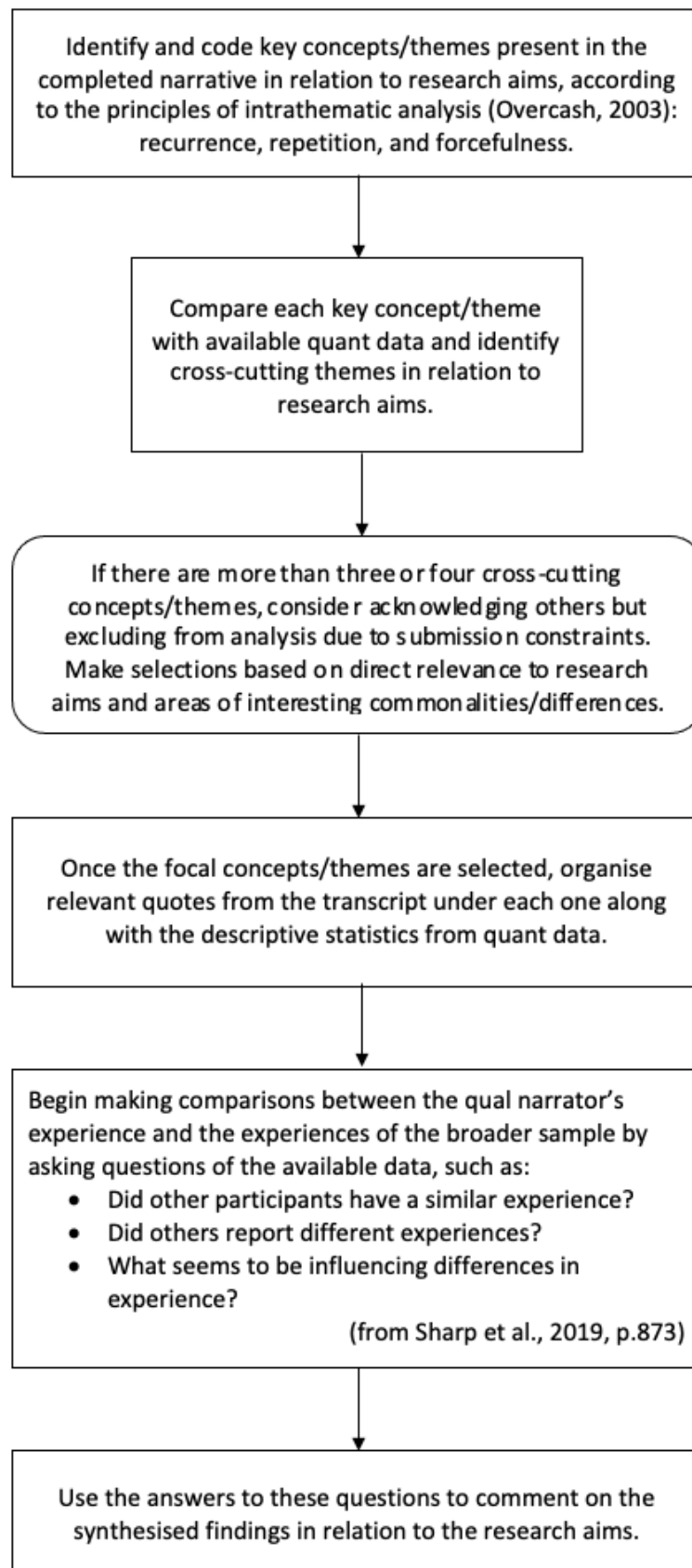
Appendix 0.2.1: Sample Quantitative Error Log

Date screened	Question ID	Case ID	Error	Correction	Comments
05/06/20	Q4 – My Family is changing – Age When Married	ADAD027	Age coded as 3 (unlikely, youngest legal age is 9 in recent history).	Re-coded to 99 (missing value) for preliminary descriptive statistics.	Requested raw data check for actual age recorded – 05/06/20.
		ADAD089 ADAD090	Age coded as 9 (unlikely, duration of marriage also coded as 9 – missing values; unable to verify).	Re-coded to 99 (missing value) for preliminary descriptive statistics.	
	Q3 – My Family is changing – Duration of Marriage	ADAD047	Duration coded as 8 (pre-assigned coding categories range 1-3; likely missing value).	Re-coded to 9 (missing value).	
	Q14 – My Family is changing – Pre-Divorce Conflict	ADAD093	Duration coded as 99 (likely missing value).	Re-coded to 9 (missing value).	
	Q15 – My Family is changing – Separation Before Divorce	ADAD029	Duration coded as 4 (pre-assigned coding categories range 1-3).	Re-coded to 9 (missing value) for preliminary descriptive statistics.	Requested raw data check for actual duration recorded – 05/06/20.
	Q9 – My Family is changing – Did you work when you were married?	ADAD006 ADAD008 ADAD036	Coded as 3 (yes or no question; pre-assigned coding categories range 1-2).	Re-coded to 9 (missing value) for preliminary descriptive statistics.	Requested raw data check for actual answer recorded – 05/06/20.
	Q10 – My Family is changing – Type of Work	ADAD022 ADAD023 ADAD024 ADAD025 ADAD026	Coded as 99/*8 (pre-assigned coding categories range 1-4; likely missing values).	Re-coded to 9 (missing value).	

Appendix 0.2.2: Analysis Plan Part 1: Qualitative Narrative



Appendix 0.2.3: Analysis Plan Part 2: Synthesising Mixed Data



Appendix 1.1: *Dementia* author instructions

Aims and Scope: “The aim of the journal is to publish original research, or original scholarship contributions, to the existing literature on social research and dementia. The journal will consider all relevant designs, methods and methodologies that meet this aim. The journal will also consider narrative-based and/or other forms of literature review that seek to answer social research questions in dementia studies; however, such reviews need to have a systematic approach to literature collation and reporting. All original research published in the journal must comply with ethical approval processes.”

Article Types: “Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.”

Formatting: “There is no need to follow a specific template when submitting your manuscript in Word. However, please ensure your heading levels are clear, and the sections clearly defined.”

Language and Terminology: “Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g., to access), and the use of adjectives as nouns (e.g., demented). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use ‘dementia-friendly’ language in positioning people living with dementia in their article and avoid using pejorative terms such as ‘demented’ or ‘suffering from dementia’.

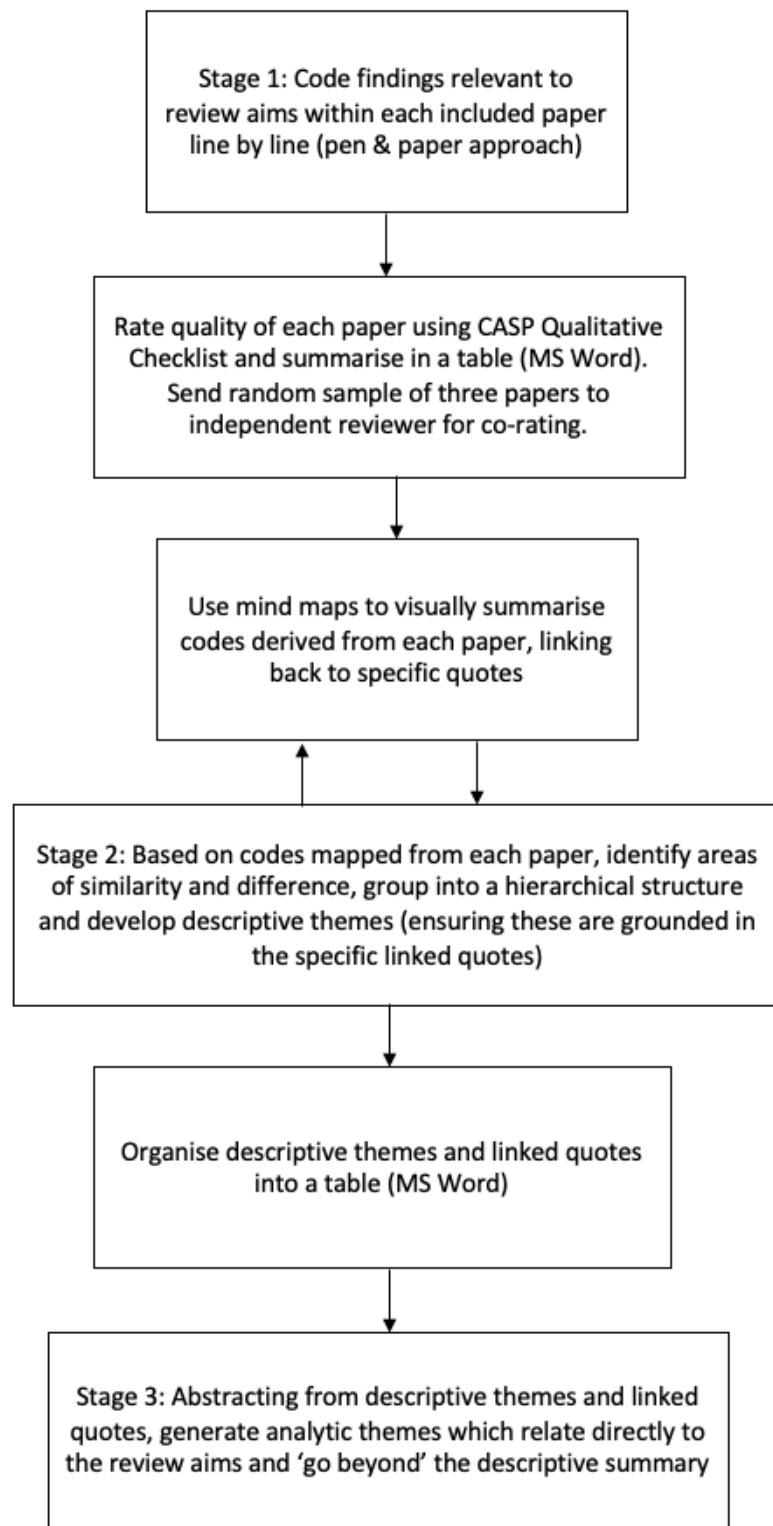
Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.”

Reference: SAGE Journals (2021). *Dementia: Manuscript Submission Guidelines*. Retrieved from: <https://journals.sagepub.com/author-instructions/dem>

Appendix 1.2: EBSCO PsycINFO Search 06/08/20

#	Query	Results
S10	S3 AND S6 AND S9	51
S9	S7 OR S8	1,203,132
S8	TI (Qualitative OR Interview* OR "Focus Group*" OR Experience* OR Perspective* OR Narrative OR Thematic OR Grounded OR Phenomenol* OR Ethnograph*) OR AB (Qualitative OR Interview* OR "Focus Group*" OR Experience* OR Perspective* OR Narrative OR Thematic OR Grounded OR Phenomenol* OR Ethnograph*)	1,203,132
S7	(MH "Qualitative Studies") OR (MH "Grounded Theory") OR (MH "Semi-Structured Interview") OR (MH "Unstructured Interview") OR (MH "Structured Interview") OR (MH "Interviews") OR (MH "Focus Groups") OR (MH "Life Experiences") OR (MH "Phenomenological Research") OR (MH "Narratives") OR (MH "Ethnographic Research") OR (MH "Thematic Analysis")	13
S6	S4 OR S5	141,951
S5	TI (Dementia* OR Alzheimer* OR Vascular OR "Lewy bod*" OR Parkinson* OR Frontotemporal OR "AIDS Dementia" OR "HIV-associated Dementia") OR AB (Dementia* OR Alzheimer* OR Vascular OR "Lewy bod*" OR Parkinson* OR Frontotemporal OR "AIDS Dementia" OR "HIV-associated Dementia")	141,951
S4	(MH "Alzheimer's Disease") OR (MH "Dementia") OR (MH "Frontotemporal Dementia") OR (MH "Dementia, Multi-Infarct") OR (MH "AIDS Dementia Complex") OR (MH "Lewy Body Disease") OR (MH "Dementia, Senile") OR (MH "Dementia, Presenile") OR (MH "Dementia Patients")	3
S3	S1 OR S2	54,694
S2	TI (Lesbian* OR Gay OR "Same sex" OR Homosexual* OR Bisexual* OR Transgender* OR Transsexual* OR Agender OR Non-conforming OR Non-binary OR Queer* OR Genderqueer OR Intersex* OR Asexual* OR LGB*) OR AB (Lesbian* OR Gay OR "Same sex" OR Homosexual* OR Bisexual* OR Transgender* OR Transsexual* OR Agender OR Non-conforming OR Non-binary OR Queer* OR Genderqueer OR Intersex* OR Asexual* OR LGB*)	54,694
S1	(MH "GLBT Persons") OR (MH "Lesbians") OR (MH "Gay Persons") OR (MH "Gay Men") OR (MH "Men Who Have Sex With Men") OR (MH "Homosexuality") OR (MH "Bisexuality") OR (MH "Bisexuals") OR (MH "Transgender Persons") OR (MH "Transsexuals") OR (MH "Transsexualism") OR (MH "Hermaphroditism") OR (MH "Pseudohermaphroditism")	3

Appendix 1.3: Synthesis process



Appendix 1.4: Additional Participants

Authors & Year of Publication	Additional Participants excluded from review
Barrett et al., (2015)	9 gay, lesbian and trans people with dementia; 6 paid service providers.
Constable (2011)	2 carers of people with dementia identified as heterosexual; and one carer did not disclose their sexual or gender identity.
McParland & Camic (2018)	10 gay male and lesbian people with dementia
Meadows et al. (1999)	3 mothers caring for their gay sons with HIV-associated dementia.
Moore (2002)	None
O'Connor et al. (2010)	1 lesbian woman with early onset “atypical vascular dementia” and her daughter.
Price (2010) **	None
Price (2011) **	None
Price (2012) **	None
Reczek & Umberson (2016)	14 gay, 15 lesbian, and 15 heterosexual couples caring for parents/in-laws (unclear whether this includes people with dementia), in mid-life.

Appendix 1.5: Descriptive themes/coding example

Descriptive Themes	Corresponding Codes (see Code Key)
(Non-) disclosure of gay, lesbian and trans identities in health and social care contexts	10. Active disclosure of gay and lesbian identity/relationship to services (to challenge or avoid assumptions)
	11. Passive disclosure of gay and lesbian identity/relationship to services (especially home care workers who will see photos and other personal objects in partners' house)
	15. (Non-disclosure of gay/lesbian identity in the context of) heterosexist/centric carer support groups
	16. Desire to maintain control over disclosure process – balancing risk of this once services involved
	17. Passive non-disclosure of gay/lesbian identity due to past experiences of homophobia and exclusion from services
	18. 'Outed by dementia' to services (various) and other residents (in care home settings)
	25. Active non-disclosure of lesbian identity rendering a partner-carer 'invisible' to services
	28. Passing as heterosexual in response to assumptions from services (e.g., assume sibling relationship with partner)
	32. Experience of 'awkwardness' around disclosure of gay/lesbian relationship to older adult services
	40. Active non-disclosure ('becoming more closeted') in residential care settings to avoid discrimination
Homophobia/transphobia /exclusion/heterosexism (anticipated and experienced) in health and social care contexts	6. Inconsistent practices of inclusion and recognition re gay identities and relationships in services
	9. Experiences of heteronormative/heterosexist practice within services (includes 'treating everyone the same')
	12. Zero tolerance of homophobia from home care workers (shown the door)
	13. Anticipating homophobic stereotypes about availability to provide care
	14. Experience of homophobic stereotypes when enacting caring role
	15. (Non-disclosure of gay/lesbian identity in the context of) heterosexist/centric carer support groups
	17. Passive non-disclosure of gay/lesbian identity due to past experiences of homophobia and exclusion from services
	20. Fears of being diagnosed with dementia due to experiences of poor quality of care from services towards the cared for person – including ageist/heterosexist settings
21. Carers planning ahead to avoid their own identities and relationships from being obscured within services should they develop dementia	

Code Key

1. Significance of social/chosen family support networks for lesbian and gay carers (which can be ignored/dismissed by services but can also influence engagement with them)
2. Carers as advocates, trainers and care coordinators, yet left to manage without support of services
3. Carers opinions/knowledge/contribution to person-centred care undermined or ignored by professionals
4. Lack of interest in carers as people, including strain of caring role and unique needs as lesbian/gay carer, and emotions
5. Lack of interest/understanding regarding pre-existing family dynamics (especially between lesbians and their mothers with dementia)
6. Inconsistent practices of inclusion and recognition re gay identities and relationships in services
7. Lack of services specifically for lesbian and gay carers
8. Experiences of flexibility, kindness and validation from services
9. Experiences of heteronormative/heterosexist practice within services (includes 'treating everyone the same')
10. Active disclosure of gay and lesbian identity/relationship to services (to challenge or avoid assumptions)
11. Passive disclosure of gay and lesbian identity/relationship to services (especially home care workers who will see photos and other personal objects in partners' house)
12. Zero tolerance of homophobia from home care workers (shown the door)
13. Anticipating homophobic stereotypes about availability to provide care
14. Experience of homophobic stereotypes when enacting caring role
15. (Non-disclosure of gay/lesbian identity in the context of) heterosexist/centric carer support groups
16. Desire to maintain control over disclosure process – balancing risk of this once services involved
17. Passive non-disclosure of gay/lesbian identity due to past experiences of homophobia and exclusion from services
18. 'Outed by dementia' to services (various) and other residents (in care home settings)
19. Support from gay partners in relation to intergenerational caregiving
20. Fears of being diagnosed with dementia due to experiences of poor quality of care from services towards the cared for person – including ageist/heterosexist settings
21. Carers planning ahead to avoid their own identities and relationships from being obscured within services should they develop dementia
22. Desire among some lesbian and gay carers for LGBTQ specific services for older people
23. Preference for inclusion in mainstream older people's services (e.g., to avoid ghetto and to preserve difference)
24. Concerns about lack of privacy in certain care contexts
25. Active non-disclosure of lesbian identity rendering a partner-carer 'invisible' to services
26. Pressure/expectations from services for lesbian partner to be involved in caring role

Descriptive theme Key:

👉 (Non-) disclosure of gay, lesbian + trans identities

👉 Homophobia/transphobia/exclusion/heterosexism

👉 Support networks/exp's of support.

👉 (Non-) person-centred / inclusive care

👉 (Dis-) respect for the privacy...

👉 Preferences for services

Appendix 1.6: CASP Findings

Criteria	Barrett et al. (2015)	Constable (2011)	McParland & Camic (2018)	Meadows et al. (1999)	Moore (2002)	O'Connor et al. (2010)	Price (2010)	Price (2011)	Price (2012)	Reczek & Umberson (2016)
Aims clearly stated?	✓	✓	✓	X	✓	✓	✓	✓	✓	✓
Appropriate methodology?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate design?	✓	✓	✓	✓/X	✓/X	✓	✓	✓	✓	✓
Appropriate recruitment?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Data collection?	✓/X	✓	✓	✓/X	✓/X	✓	✓/X	✓	✓	✓
Reflexivity and bias?	✓/X	✓	✓	✓/X	✓/X	✓/X	✓/X	✓/X	✓/X	✓/X
Ethical issues considered?	✓	✓	✓	✓/X	✓/X	✓/X	✓/X	✓	✓	✓

Rigorous analysis?	✓ / X	✓	✓	✓ / X	✓ / X	✓	✓ / X	✓	✓ / X	✓ / X
Findings clearly stated?	✓	✓	✓	✓*	X	✓	✓	✓	✓	✓
Valuable in context?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
✓ = Yes, ✓ / X = Can't tell (opaque reporting), X = No. *Although source of participant quotes not reported (e.g., whether carer is a friend or mother).										

Appendix 2.1: *Feminism & Psychology* author instructions

Aims and Scope: “*Feminism & Psychology* provides an international forum for debate at the interface of feminisms and psychologies. The peer-reviewed journal's principal aim is to foster feminist theory and practice in - and beyond - psychology. We are interested in pieces that provide insights into gendered realities along multiple intersecting dimensions of difference, privilege, and inequality. In addition to empirical work, we invite critical engagement with theories, methods of inquiry, concepts, and disciplinary and professional practice.”

Article Types: “*Feminism & Psychology* welcomes manuscripts in a variety of formats, including work that introduces innovative forms of feminist psychology scholarship. *Feminism & Psychology* publishes the following kinds of pieces: [...] empirical articles (up to 8000 words) [...] Articles should include abstracts of no more than 200 words. Please note that references and tables in the body of the manuscript are included in the total word count.”

Formatting:

“Use font 12 throughout.

Use left justification and double spacing for the entire manuscript.

Extracts of data should be indented but should be of the same font as the main body of the article and should be double spaced.

Please ensure pages are numbered.

Please clearly distinguish between levels of headings in the manuscript.

1st order: Bold, sentence case, roman, left-aligned

2nd order: Italics, sentence case, left-aligned

3rd order: Italics, sentence case, left-aligned, followed by period, followed by run-on text

4th order: Italics, sentence case, slightly indented heading, followed by period, followed by run-on text

DO NOT use the heading Introduction at the beginning*”

*Please note this heading has been used for the purpose of this Thesis.

Reference: SAGE Journals (2021). *Feminism & Psychology*: Manuscript Submission Guidelines. Retrieved from: <https://journals.sagepub.com/author-instructions/FAP>

Appendix 2.2: Ethical Approval (An Najah University)

An-Najah
National University
Faculty of medicine Sciences &
Health
Institutional Review Board



جامعة النجاح
الوطنية
كلية الطب وعلوم الصحة
لجنة الاخلاقيات البحث
العلمي

Ref: Oth' Dec. 2020/18

IRB Approval Letter

Study Title:

“Understanding the Experience of Divorced Women in Palestine ”

Submitted by:

Caesar Hakim, Hamish McLeod, Naomi White, Jennifer Malik

Date Approved:

27th December 2020

Your Study Title “Understanding the Experience of Divorced Women in Palestine ” viewed by An-Najah National University IRB committee and was approved on 27th Dec. 2020

Hasan Fitian. MD



IRB Committee Chairman

An-Najah National University

نابلس - ص.ب 7 أو 707 || هاتف (970) (09) 2342902/4/7/8/14 || فاكس (970) (09) 2342910

Nablus - P.O Box :7 or 707 | Tel (970) (09) 2342902/4/7/8/14 | Faximile (970) (09) 2342910 | E-mail : hgs@najah.edu

Appendix 2.3: Ethical Approval (University of Glasgow)



Professor Hamish McLeod

MVLS College Ethics Committee Project Title
Understanding the Experiences of Divorced Women in Palestine
200200096

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study.

We are happy therefore to approve the project, subject to the following conditions.

- Parent project approvals and consent allow for sharing and analysis of data as described in this proposal.
- There are no protected or sensitive data and no risk of participant identification.
- Project end date as stipulated in original application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:
(http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report within 3 months of completion.

Yours sincerely

Dr Terry Quinn

Terry Quinn
FSO, FESO, MD, FRCP, BSc (hons), MBChB (hons)
Senior Lecturer / Honorary Consultant

College of Medicine, Veterinary & Life Sciences
Institute of Cardiovascular and Medical Sciences
New Lister Building, Glasgow Royal Infirmary
Glasgow
G31 2ER
terry.quinn@glasgow.gla.ac.uk
Tel – 0141 201 8519

The University of Glasgow, charity number SC004401

Appendix 2.4: 'My family is changing' Survey



Guidance and Training Center for the Child and Family
مركز الإرشاد والتدريب للطفل والأسرة

Survey: My family is changing

Name (could be an alias) _____

1	Gender	<input type="checkbox"/> Female <input type="checkbox"/> Male			
2	Age				
3	Duration of marriage:				
4	Age when married:				
5	Area of residence:	<input type="checkbox"/> Camp <input type="checkbox"/> Village <input type="checkbox"/> City			
6	Duration of the engagement period before marriage:				
7	The type of marriage:	<input type="checkbox"/> Traditional <input type="checkbox"/> Non-traditional			
8	Number of children:				
9	Were you working when you were married:	<input type="checkbox"/> Yes <input type="checkbox"/> No			
10	Type of work:	<input type="checkbox"/> Freelancer <input type="checkbox"/> Employee <input type="checkbox"/> Student <input type="checkbox"/> N/A			
11	Average number of working hours per day:				
12	Income	None	1500-2500	2500-4000	More than 4000
13	Date of divorce:				
14	Duration of disagreement before the divorce:				
15	Duration of separation before the divorce:				
16	Educational background:				
17	Your kinship with your partner:				
18	Living:	<input type="checkbox"/> Living dependently <input type="checkbox"/> Living independent			



During the period of marriage

* To what extent was there sharing taking on the following responsibilities of the house?		My responsibility	My responsibility along with my partner's assistance	Shared responsibility	My partner's responsibility along with my assistance	My partner's responsibility
19	Cleaning the house daily					
20	Cleaning the house periodically (Windows, walls...)					
21	House maintenance					
22	Following up on bills					
23	Car maintenance					
24	Buying household- and children-related items					
25	Food preparation					
26	Looking after the children					
27	Taking important decisions (Housing, Children's					



	education, work...)					
28	Daily decision making (Visits, leisure)					
29	Taking decisions to spend a large amount of money (Car, house)					
30	Taking decisions to spend a small amount of money (Daily expenses, leisure, clothes...)					
31	Teaching the children					

* Our marital relationship during marriage		Happens rarely	Happens occasionally	Happens frequently
32	The small discussions were usually heated up and turned into a violent argument characterized by mutual accusations, criticism, verbal abuse, and pointing to previous mistakes			



33	My partner criticized and marginalized my opinions, my feelings or my desires.			
34	My partner seemed to understand my words and actions to be negative which was not what I meant.			
35	When solving one of our problems, it seemed as if we were two opposing teams.			
36	I seriously considered how my marital relationship would be with another partner			
37	I felt lonely during my marital relationship			
38	When we argued, one of us avoided finishing the discussion that was related to the dispute, or would leave the place.			

The reasons that led to the divorce		Never	Rarely	Sometimes	Often	Always
39	Problems with the partner's family					
40	Child rearing					
41	Economic problems					
42	Alcohol addiction or other addictions					
43	Verbal abuse					
44	Physical violence					
45	Lack of emotional interest					
46	Family interventions					



47	Controlling partner					
48	Arguing over role distribution					
49	List any other reasons:					

When we had a disagreement, we		1- Yes	2- No
50	Tried to solve the disagreement between us		
51	Requested family support to solve the disagreement		
52	Requested support from friends		
53	Sought support from clergy men		
54	Sought support from institutions and specialists.		

During the divorce procedures:

55. Who made the decision to divorce?	Only me	Only my husband	A joint decision

56. Did you receive support during the period of finalizing the divorce?		Yes			No
57. If your answer was yes, which party provided you with the	Family	Friends	Clergy men	Institutions and specialists	List any other parties:



support when finalizing the divorce?					
---	--	--	--	--	--

58. What was the type of support?	Legal	Psychological	Trying to solve the disagreement	List any other types:

Evaluate the type of support you received?		Poor	Good	Somewhat good	Very good	Excellent
59	Legal support					
60	Psychological support					
61	Trying to solve the disagreement					

After the divorce

Challenges		Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
62	I feel that the community is rejecting me					
63	I feel that the community is looking at me negatively					



64	I think that the laws and regulations do me justice					
65	I feel that my family does not support me or support my choices					
66	I feel that the community is keeping an eye on my social relationships					
67	I feel that my economic situation is dependent on the support of my family and relatives...					
68	I feel that I will have less time to spend with my children after the divorce					
69	I feel that I will have more freedom after the divorce					
70	I feel that I have more freedom and independence now than during my marriage.					

A look into the future		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
71	I feel that I can raise my children on my own					



72	I feel that I am able to overcome the challenges of society					
73	I believe that I can start a new relationship with a new partner					
74	I feel that I will have the freedom to act.					
75	I feel that I will have the freedom to make my own decisions					
76	I believe that I will change the society's negative perception of divorced women.					

Appendix 2.5: Interview Topic Guide



Guidance and Training Center for the Child and Family
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An interview Guide: My family is changing

- Age: Area of Residence:
- Age when married: Level of education:
- Duration of the marriage: Date of divorce:
- The number and age of children after the divorce:

Section	Questions
Challenges during the marriage	<p>1- Tell me about your marriage experience? What does marriage mean to you?</p> <p>_____</p> <p>_____</p> <p>2- Tell me about the distribution of roles between you and your husband in terms of duties and responsibilities?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>3- What were the most difficult things for you during your marriage, and what did you do about them?</p> <p>_____</p> <p>_____</p>
The causes and consequences of divorce	<p>1- In your opinion, what led you to ask for a divorce? In case your husband was the one to ask for a divorce, in your opinion, what prompted him to do so?</p> <p>_____</p> <p>_____</p> <p>_____</p>



	<p>2- Can you describe how you felt during that period?</p> <hr/> <hr/>
	<p>3- How did you treat your husband during that period, and how did he treat you?</p> <hr/> <hr/> <hr/>
	<p>4- How did you imagine your life would be after the divorce? (To check the expectations).</p> <hr/> <hr/>
	<p>5- How was the reaction of your parents and the people surrounding you?</p> <hr/> <hr/>
	<p>6- How was the reaction of your children?</p> <hr/> <hr/>
The psychological state	<p>1- Describe the effect of the divorce period on your psychological state compared to the period of when you were married?</p> <hr/> <hr/>
	<p>2- What are the most difficult situations that happened to you? How did you deal with these difficulties? What helped you overcome these situations?</p>



	<hr/> <hr/> <p>3- Do you think that there are still any unsolved matters related to the marriage? If yes, what are they and how do you want to solve them?</p> <hr/> <hr/> <hr/>
After the divorce	<p>1- Can you tell me how you see yourself now, and how your life became after the divorce?</p> <hr/> <hr/> <p>2- What are the challenges you face during this period?</p> <hr/> <hr/> <p>(If you work): How is your working life affected?</p> <hr/> <hr/> <p>(If you don't work): How is staying at home affecting the quality of your life?</p> <hr/> <hr/> <p>3- Can you tell me how these challenges affected you? How do you deal with them?</p> <hr/> <hr/>

Appendix 2.6: Polkinghorne narrative analysis criteria

- a) Descriptions are included of the cultural and social context of the story.
- b) Information is provided about the subject of the story (the research participant), for example, their age, developmental stage, and other information relevant to the aims of the research.
- c) Explanations are included of the relationships between the participant and other significant people in their life.
- d) The story concentrates on the goals, choices, interests, plans, purposes, and actions of the participant, on their meanings, and on their vision of the world.
- e) Recognition is given to historical experiences and events that have influenced the participant's life story.
- f) The story is bound by time; it has a beginning, middle, and end.
- g) The narrative offers a meaningful explanation of the participant's experiences and actions, drawing together separate data elements in a credible and understandable way.

(from Polkinghorne, 1995, cited in Sharp et al., 2019, p.871)

Appendix 2.7: Narrative source quotes (line numbers)

“Marriage resembles stability, security, love. [...] ...it means everything. These are the things that I didn’t have.” (10-15)

Getting to know each other:

“I advise every woman who will get married to take a period of time in order to discover her partner, not to get married right away. To identify their priorities in life, what her partner likes or dislikes, to be fully acknowledging each other’s personalities, for example not to get married without knowing each other. To always ask, to know each other more before they are married.” (19-23)

Hopes for marriage (as a kind of equal partnership):

“That someone would contain the other person, and there would be a compatibility in their thinking. That someone would excuse the other person. There would be sympathy, tenderness, love, forgiveness. To forgive the other If someone was mistaken to receive forgiveness from the other.” (10-13)

“If any problem/ situation happens to be able to solve the problem, and if they couldn’t to seek help from another person in order to help them solve this problem. Not to allow problems to grow bigger, and not to allow anyone to interfere in their relationship, like his mother, his parents or her parents. They are not a positive effect.” (23-26)

Realities of marriage (lack of communication, privacy and mutual understanding):

“It was difficult to communicate with him. And everything that happens in our relationship, he would tell his parents about it. There are no secrets between us and

no privacy [...] sometimes I become shocked when his mother or sisters or his cousin talks about some things that happened between me and my husband.” (73-78)

“He would expose me in front of his mother and relatives by saying the private secrets that happen between him and I. It was a very difficult situation for me, it was beyond my ability to tolerate. Meaning that there was no privacy, it was totally absent. It was too intolerable to the extent that if I wanted to go out to buy a pair of trousers, all the family members would know. It was forbidden to go buy something or to bring something for the house and keep it hidden or secret from his family/ his parents. I had to tell them everything I do. This was the hardest thing I have faced.” (80-87)

“...I think if he gave me a chance or space to try to understand each other more, to love each other more, but he always put a wall between us, I used to say maybe he should have allowed the space between us for understanding we wouldn't have reached the divorce decision. This is the thing that I think about the most. But this is God's will, this is what God wanted.” (314-318)

“...I was living in a prison in this marriage.” (144-145)

Marital difficulties started from day one:

“My marriage experience was short but very difficult starting from the first day of marriage until the divorce. [...] It was a difficult experience, there was no understanding between me and my divorcee. Maltreatment, meaning that he treated me badly, there was no respect, also no love, he didn't love me, and he didn't even try to love me.” (2-6)

Strict gender roles/expectations:

“...he didn't help me at all. He didn't even listen to me or he didn't know what was wrong with me, everything was a burden for me. also, he imposed on me to help his parents despite me being sick or tired or I don't feel like helping he would not excuse me, but it was like an obligation to me, when I tell him I'm not able to help, this would create a problem between us.” (33-37)

“...after giving birth, when I get discharged from the hospital, and I return home, I start cleaning and tidying the house in the same day. I mean that during the period of being in the hospital after giving birth, the house will become very messy. I go home and I react negatively, I start wondering 'why is the house so messy and dirty. I am not at the house during this period but why is the house so messy?'" (38-42)

“I used to execute orders only. do this or that! So, I do what I am told to do. I am forbidden to say no.” (45-46)

“...when I need something from the supermarket, he wouldn't allow me to go and buy it, he would say: 'tell me what you need, and I will buy it for you'.” (53-34)

“It was forbidden to go buy something or to bring something for the house and keep it hidden or secret from his family/ his parents.” (84-86)

“The (sexual) relationship between my husband and myself was not good. It had many bad things for me, he had an angry temper, he would hit me, and he didn't admire anything I offer, he wanted me to do/ be like someone's wife, or he would tell me to do like something he shows me in a video. I didn't accept to do what he asked. These things are different abilities in different people, my body my abilities are different than someone's wife. He would tell me that he wants me to be as he

pleases/ as he wants. This is a major problem. He would complain to my parents and his parents. This was also a difficult challenge for me.” (89-96)

Contrast with her own background (e.g., being shouted at):

“...I originally lived in an environment that was different from my divorcee’s environment, so when he gets angry, even on the stupidest thing, he would scream and shouts. I wasn’t used to this kind of behaviour, because it didn’t happen at my parents’ house. When it happened during marriage, I would suddenly freeze, and start crying I wasn’t capable to stand for myself/ defend myself. All this happened throughout 3 years, this was the hardest thing. Sometimes a fight or a conflict starts when there is nothing really to fight/ argue about.” (65-71)

“...I ended up living with a person that does not want me or love me and he is only waiting for me for one time to say no about something that he asks of me and that would create a problem.” (140-142)

Impact on children/parenting:

“When my husband came home my older son would suddenly become angry and start hitting his head to the wall and from a wall to another, and he was only two years...” (154-156)

“Even my children during that time I wasn’t able to give them even 1% of my role as a mother...” (129-130)

Process of isolation from family:

“Even if I want to go out to visit my mother, my parents, I could do that only with his permission or according to his current mood today. For example, if I feel like visiting my parents today, but he says don’t go today go tomorrow I have to listen even if I want to go today and I don’t want to go tomorrow I had to follow his orders.” (46-49)

“...I was deceived. He used to say that he loved me and that he wants me when there were other people sitting with us. And when we are together alone, he despises me (he doesn’t stand me) and he doesn’t stand seeing me. when my uncle or a relative from the family visits us he would say I adore her and show his fake feelings and deception in front of them. It was very hurtful for me.” (171-175)

“...I stopped communicating with my family and parents because they (he and his parents) told me that they are the root cause of the problems that happen between us. I stopped communicating with them for two months. The problems increased and my husband’s family stood against me more because I could no longer tell my family so that they can stand up for me and help me.” (108-122)

“I was living in a state of conflict like being in a whirlpool all the time. I have to end this situation; I am unable to live with him or his parents anymore...” (105-106)

Increasing severity of abuse, attempts to forget:

“...violence, the verbal abuse, the hate. Hate, because I don’t want to say there wasn’t love. Hate, I used to see the hate in his eyes, he wished not to see me. he wished that I will be buried away underground so that he wouldn’t see me.” (150-152)

“His parents increased their interferences in our life, and they did horrible things. I forgot all the details and I don’t like to remember them however their interferences were too much...” (112-114)

Reaching out to uncle at height of crisis and leaving without her children:

“I called my uncle and told him there has been problems between me and my husband’s family. At that time, I wasn’t talking to my parents, I told my uncle unless you come and take me today, I will go to the third floor and commit suicide by dropping myself down. He told me to calm down, I told him that I don’t want my children or a husband or parents. I was living in a horrible conflict; I told my uncle either you come to take me, or I no longer want this life. And actually, my uncle really came to take me this day, I didn’t expect him to come to take me from this place and that I will no longer come back, I went out with the clothes that I was wearing I didn’t take anything with me, I didn’t take my children because their grandmother refused that I take them with me, she told me that’s enough leave, and I didn’t return this day.” (114-123)

“It was difficult to live with a person like that even if there were children. I sacrificed my children, but my divorce was better for my children.” (152-154)

“My mother used to tell me that only children tie the husband to his wife, and I used to say no any woman even if she has 10 children this doesn’t necessarily tie the husband to his wife in such a bad situation with many problems” (166-168)

Family adjustment period before standing by her:

“This was what God destined for me, my parents didn’t understand my situation, but my uncle understood it. I stayed at my uncle’s house for two days then my parents gradually started comprehending the idea of separating and getting my divorce, and understood that my husband didn’t love me and that it is hard for me to stay with him in the relationship in that bad situation, so that’s it the divorce relieved me so much, if I wanted to stay further in this relationship, maybe many very bad things could have happened.” (123-129)

“My parents were convinced eventually, and my father said that he was relieved that his daughter (me) has returned home again. I felt the same as my father I was relieved. My mother and siblings and relatives felt the same, like my father and myself.” (217-219)

“...they knew I faced a lot of unfairness during my marriage and that after divorce I no longer live in that situation. I felt that my family and my uncles stood by my side and backed me up with the decision of the divorce.” (228-230)

“...the first day of receiving my divorce I was free like a bird...” (147-148)

Fear of husband/in-law influence on day of divorce:

“...he started saying in front of people that he still wants me, but it was all a lie, even in the day at the court, he passed by me as if he didn’t know me or has never seen me in his life. Other women told me this is your divorcee, and I said: yes.” (189-191)

“...he and his father acted as if they didn’t know me and have never seen me before. so, I acted normally to that situation, but when I signed the paper, I was very scared but the thing I went through has suddenly disappeared from my life.”
(191-194)

Relief when divorce finalised:

“I mean the first day of my divorce, when I was in the court I felt as if a knife stabbed me when we finished signing the divorce papers and then I felt that marriage was a burden that was lift of off my chest. I felt such a huge energy and lightness in my heart. I never forgot that feeling because I never lived it before. I thought how God can lift away such huge chaotic world that I lived in in just one moment of divorce when I was in court. Unbelievable feelings of comfort, I cannot even describe the feeling to anyone. I felt like cold iced water was spilled on me from the sky.” (178-184)

“Of course, he was happy, he experienced the same feelings as mine.” (186)

Expectations of restricted life with family of origin:

“I was sure I wasn’t going to be happy, and that I will be imprisoned, or I will not be free or be able to go out as I want, I left the idea of going back to university to study. I even said it is impossible to return to my work at the municipality. But thank God I considered all these fears that I used to think about as a burden, however I was able to overcome the fears during the first day of taking my divorce.” (198-203)

“I expected that I will stay at home, not to be able to move freely or go out as I want. I will only be limited to going for visits with my mom to our relatives’ house. This is what I imagined. I imagined that I won’t be able to live my life in a good way, that I will have many limitations and restrictions: limited relationships. As my parents wanted.” (205-208)

Family of origin ?attempting to preserve honour:

“When I got divorced, I was pressured by my parents, siblings, relatives and surrounding people. Meaning that I got divorced as a virgin, and my kids were born as a mistake, they indicated that I gave birth through caesarean procedure, but I am still a virgin. This annoyed me so much because I gave normal birth to my 2 children and I suffered in both births.” (96-100)

Finding freedom within family of origin:

“...I was scared of my parents. But my parents and siblings are providing me the freedom to go wherever I want and participate in any activity. If I leave the house, I don’t need to inform my father that I left. Thank God, he trusts me. he told me the most important in relationship is trust. I have this trust, I go to the university, or elsewhere, I have established a trust relationship with my parents.” (327-331)

“I had fears that I will not return to the municipality, but my father understood and knows what I am, I go to the municipality and I participate in the board sessions like any other member. Even if the sessions stay until nine or ten in the evening, and I was late to return to the house, my father is understanding that I am at work. Even if I return at 10 or 10:30 they drive me home. I never imagined my life will be like this.” (335-340)

“I changed a lot after divorce, I became a strong woman.” (262)

Finding strength in divorce:

“It’s not weakness when a woman says, ‘I want a divorce’. I am strong because I was able to put a limit to the pain that I was living in.” (345-346)

Life becoming filled with personally meaningful activities:

“...after divorce I registered at the university to study and I returned to work at the municipality. Life looked beautiful in my eyes.” (208-210)

“I started studying and becoming educated and reading. I also took courses here and in other places about gender. I didn’t let anything go without taking benefit from it (meaning workshops and courses) throughout the summer break I didn’t stay at home. I took a first aid course and another course in English conversation. I took these courses and I improved myself and fulfilled my free time with different things.” (292-296)

“My teacher felt that I have this huge energy, so he calls me for every activity or workshop at the university. He registered me in two courses at the university, I am presenting my university in one of the courses with other universities also. A group of universities are participating, and I am among 4 students represented from my university at the course. This thing makes me very happy, that many people senses that [Munira] has something.” (351-356)

“...in the organization where I practice, I discovered a talent of drawing on walls, huge drawings, with many colours, and it would turn out a very beautiful drawing. I thought about drawing one day but I never expected that I am able to draw a

painting on a big wall. This thing made me very happy. I started working on the beautiful things in me. hopefully I will continue with this much strength.” (359-363)

Developing personal identity, skills and abilities in divorced life:

“I changed a lot after divorce, I became a strong woman. I started helping myself, to improve myself, I socialized more with people, I returned to study, and this helped me a lot. I met new people, I am a very active person and I participate in different initiatives and institutions, and different workshops with the university or within the scope of the university. I met so many people. I felt that life is beautiful after divorce and its different than when I was married. Now I am living my freedom and I say what I want whenever I want. My parents are very cooperative with me, I used to have many fears when I was married about ‘how will I get a divorce’ all these fears are gone. It is enough for me that I returned to the university and soon I will graduate.” (262-270)

“no one controls me, or humiliates me psychologically, I am living as I want. I’m a student at the university, soon to graduate, I work as a member of the board in my town along with 11 men. There is only me and another woman, and we are all 11. [...] I go to the municipality and I participate in the board sessions like any other member.” (333-337)

“the stuff that were considered like a weakness point for me during marriage period I started improving them after I got divorced. For example, I had social phobia, but not anymore, I wasn’t social I wasn’t meeting people or mingling with them, but I overcame this thing. I also was very sensitive, any word can upset me, and I would start crying right away, but currently not. Because I worked on improving myself.” (306-310)

Improving relationships with children:

“I sacrificed my children, but my divorce was better for my children. [...]

Currently I see my older son’s language is good, his health is good, he is like the children of his generation and more beautiful even.” (153-158)

“...currently my children come to visit, and I became capable to give them much more than I used to before, they are growing up and my relationship with them is very good. There is a state of stability between my children and myself. Thank God. If I was still living with them, I wouldn’t have been able to give them 1% of my role as a mother.” (130-134)

“I stayed for more than 3 months without seeing my children, because my husband’s family have forbidden me. I saw my children -after some months. My younger child when he was one year old, I saw him -after some months without seeing them I felt that he is very scared of me. I heard the word Mom from him after 7 months of constantly seeing him.” (241-245)

“...currently my relationship with them is very strong. But at the beginning I struggled so much because they would wake up at night asking for their father. They used to wake up at night and cry, but they no longer do that now, they sleep all night. They come to our room and they know that this room is mine and theirs with a cupboard full of their toys.” (245-249)

“...I advise every woman who experiences domestic violence not to stay silent and to seek help from specific institutions.” (282-3)

Moving forward, helping others, a life of her choosing:

“I talk about my experience wherever I go for example I talk about it at GTC. I talked about my experience during a workshop at [universities]. I talked about my experience and I advise every woman who experiences domestic violence not to stay silent and to seek help from specific institutions.” (280-283)

“what helped me deal with the situation is my experience here at GTC. It helped me so much by providing me support, and I became more aware of myself, I started feeling that my problem is normal compared to other problems, I started attending GTC and meeting people and knowing more about different problems of other people, my problem is nothing. Today I heard the problem of another woman’s story and I felt that my problem is nothing.” (287-292)

“no one controls me, or humiliates me psychologically, I am living as I want. I’m a student at the university, soon to graduate...” (333-334)

Appendix 2.8: Cross-cutting themes

- Marrying at a young age after a brief engagement period – time spent ‘getting to know’ a prospective spouse
- Alone in cleaning/caring for the household (besides financially)
- Lack of communication during marriage
- **Domestic abuse/coercive control during marriage***
- Family involvement in conflict resolution between married couples
- Religious coping – it was God’s will, it’s what God destined me for etc.
- **Family support with and following divorce process***
- **Expecting and leading restricted lives vs free/independent lives following divorce***
- Developing sense of self/self-confidence following divorce
- Outcomes in terms of working, studying etc.
- Contact with children following divorce

*themes selected for synthesising mixed data