Report on Research about
LGBT Carers

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count me in too
LGBT research information desk

About Count Me In Too

Count Me In Too is a community-led action research project that seeks to advance progressive social change for LGBT people in Brighton & Hove. The Count Me In Too research project built on learning from the Count Me In research project in 2000 and other local research into the experiences of local LGBT people. Data was gathered from LGBT people who live, work and socialise in Brighton & Hove. In 2006, 819 people completed questionnaires and 69 people discussed issues in focus groups. These included LGBT people with shared identities, such as older people, young people, Black & Minority Ethnic people, parents, hate crime survivors and Deaf people.

The data was initially analysed by an Action Group composed of local LGBT people, and initial findings were published in June 2007 in an academic report with a parallel community report. In the past two years, the project has produced 9 detailed reports with LGBT people and local service providers on a range of themes. Additional themed analyses reports have reported on Domestic Violence and Abuse, Safety, Housing, Mental Health, General Health, Bi people and Trans people. They have recommendations on how to address issues and needs identified from the data.

A series of community summaries provides a 'taster' of each additional themed analysis report. All of the reports published by this project and further information about the project, can be accessed at our website: www.countmeintoo.co.uk. To contact Count Me In Too, email lgbtresearchdesk@brighton.ac.uk or visit www.countmeintoo.co.uk.

About the LGBT Research Information Desk

The research information desk was set up in 2009 to support LGBT individuals, groups and communities in identifying evidence that can be used to strengthen funding bids, to inform service development, and in campaigning and advocacy work. The Research Information Desk signposts published research from the Count Me In Too project and other LGBT-related research from around the world, and also offers the opportunity to access summaries of as-yet unpublished data from the Count Me In Too research.

The Research Information desk is staffed by Nick McGlynn, a research project assistant for Count Me In Too, and is based at the Cockcroft Building of the University of Brighton (Moulsecoomb campus). It is supervised by Dr. Kath Browne and overseen by the Count Me In Too research team.s

About this report

Count Me In Too was designed to explore the diversity within the LGBT grouping and collated information about lesbian, gay, bisexual and trans people, recognising the similarities and differences across this grouping. A focus on inclusivity has been at the core of Count Me In Too's research and is reflected in its findings reports and recommendations.

Where requests to the LGBT Research Information Desk focus only on specific communities and identities, reports focus on these groupings.

Findings from other research projects described in this report use terms consistent with the original research, rather than those used by Count Me In Too. The Research Information Desk performs systematic searches for research on lesbian, gay, bi and trans identities: this external research may only address a particular constituency (such as 'gay men' or 'trans women'), and thus may deliberately or inadvertently exclude some LGBT identities or groupings. Where an absence or paucity of data regarding one of these identities was found, this is indicated in the report.

Summary of Key Findings

Searching published research to address a wide-ranging inquiry about unpaid LGBT carers, this enquiry found a distinct paucity of research information about LGBT-related care work and LGBT carers who are not involved in HIV/AIDS care work. The research studies identified key issues for LGBT carers and suggested that worthwhile further research could be carried out into almost every aspect of LGBT carers' lives. The majority of the research found pertained to HIV/AIDS care work (primarily involving gay men and most frequently situated in urban California).

The terms 'care', 'carer', 'caring', 'care work' and 'caregiver' were used throughout the research publications and with little in-depth analysis of the terms. The wide number of terms used is reflected in the terminology of this summary report. Most of the research considered 'care' to involve both emotional and instrumental/practical support for another individual, and research focused on paid care work (such as performed by nurses and professional carers) was filtered out.

Research on LGBT carers unanimously found that being 'out' about carer's sexualities and sexual identities is beneficial for their wellbeing, while not being out can increase stress for carers. Some choose not to be out so as to gain legitimacy as a carer, to ward off bad reactions and to protect those they are caring for (Mullan 1998, Aronson 1998, Fredriksen 1999, Orel 2006, Brotman et al 2007). Evidence suggests that the oldest and the youngest carers may be the least likely to be out (Mullan 1998, Orel 2006).

For gay and lesbian caregivers, involvement in gay and lesbian communities may be an important determinant of support (Aronson 1998, Turner et al 1998). However not all carers draw on this support, and some – such as parents – can be isolated from them, as Hicks' research in the UK found, drawing on data from his interviews with 40 gay and lesbian carers and thirty social workers (Hicks 2006). Relying on caring/support networks based on shared identities such as lesbian, gay or trans to 'pick up the slack' can be problematic due to internal differences between those defined as within the LGBT collective (Aronson 1998, Cant 2004, Hines 2007). Peer support is usually seen as the 'best' form of support for LGBT carers.

Research on familial caring relationships in particular has historically been highly heteronormative, assuming and tacitly encouraging heterosexuality (particularly as it relates to kinship and reproduction) while making homosexuality invisible and/or devalued (Aronson 1998, Mullan 1998, Turner et al 1998, Manthrope 2003, Orel 2006, Hicks 2006, Brotman et al 2007). Yet contrary to popular discourse, lesbians and gay men can have extensive familial caring duties. Gay and lesbian parents can be excluded from 'mainstream' LGBT scenes and networks; however Hicks' research reveals that they can also speak and act in ways that can marginalise non-parents, particularly by 'riffing' on broad societal themes such as ir/responsibility (Hicks 2006). Familial responsibilities – such as to children or grandchildren – can result in stress and/or conflict between carers and their partners (Orel 2006). Additionally, while peer support is usually identified as the best form of support for LGBT carers, the research found that LGBT carers' biological families are by no means necessarily hostile and that they may be a neglected source of support.

There is some work on lesbian carers but all of the research on this area recommends that more research is carried out. As Aronson and others point out, there are specifically lesbian issues for lesbian carers (as opposed to broader gay or LGBT issues) – for instance, there were particular differences between lesbian carers that were frequently made 'invisible' (Aronson 1998). This may suggest similar internal differences in other specific LGBT communities and networks (eg. within trans communities, gay male communities, etc), in which specific illnesses or configurations of class, race and so on impact on LGBT carers' lives.

Studies on trans carers were particularly scarce. Some work by Hines notes that trans care networks are seen to 'fill the gap' left by official support services. However, she also found that the differing approaches to varied trans identities in these networks leads to very different levels of commitment to care and engagement/disengagement at different times. This may highlight wider problems when imagining 'community'-based care based on shared identities (Hines 2007). Trans carers suggested that educating people about trans issues and 'giving something back' should both be considered key ethics of care, expanding the notion of what counts as care work (Hines 2007).

Although there is a lot of published research on HIV/AIDS carers much of it was carried out in the USA, and in Los Angeles and San Francisco in particular. Additional research into HIV/AIDS carework might benefit from further studies in a wider variety of locations. The 'dual stigma' of an LGBT identity and HIV/AIDS was raised by several pieces of research, which can work in tandem to negatively affect the lives of the carers of those living with HIV/AIDS. Other research revealed the importance of an intimate and positive relationship for LGBT HIV/AIDS carers and those they care for. Finally, some of this research brought up the role of religion and spirituality – this is not considered by the majority of studies into LGBT carers, and while the evidence surrounding this is slight at the moment, it may be a useful area for future work.

Contents

1 - Introduction

1.1 Introduction

Information about research into LGBT carers was researched and collated by Nick McGlynn, research project assistant with the Count Me In Too research project in December 2009, and written by Nick and the Count Me In Too research team including Dr. Kath Browne and Leela Bakshi. This information was requested by the Adult Carer's Team Manager at the Carers' Centre in Brighton to help build an evidence base for future work. This report will summarise key findings from the research on LGBT carers (with salient examples) and provide a detailed bibliography of sources.

This first section of the report provides the background of this report, including information about the Count Me In Too project, and about the methods and methodology used by the LGBT Research Information Desk to produce this research.

1.2 Count Me In Too LGBT Research Information Desk

Count Me In Too is a community-led action research project that seeks to advance progressive social change for LGBT people in Brighton & Hove. The Count Me In Too research project built on learning from the Count Me In research project in 2000 and other local research into the experiences of local LGBT people. Data was gathered from LGBT people who live, work and socialise in Brighton & Hove. In 2006, 819 people completed questionnaires and 69 people discussed issues in focus groups. These included LGBT people with shared identities, such as older people, young people, Black & Minority Ethnic people, parents, hate crime survivors and Deaf people. The data was initially analysed by an Action Group composed of local LGBT people, and initial findings were published in June 2007 in an academic report with a parallel community report. Since then the project has produced 10 detailed reports with LGBT people and local service providers on a range of themes.

The research information desk was set up in 2009 to support LGBT individuals, groups and communities in identifying evidence that can be used to strengthen funding bids, to inform service development, and in campaigning and advocacy work. The Research Information Desk signposts published research from the Count Me In Too project and other LGBT-related research from around the world, and also offers the opportunity to access summaries of as-yet unpublished data from the Count Me In Too research. The Research Information desk is staffed by Nick McGlynn, a research project assistant for Count Me In Too, and is based at the Cockcroft Building of the University of Brighton (Moulsecoomb campus). It is supervised by Dr. Kath Browne and overseen by the Count Me In Too research team.

1.3 Research Question and Methods Used

In November of 2009, the Count Me In Too LGBT Research Information Desk was asked to provide a summary of Count Me In Too's data regarding Q.58 of the Count Me In Too questionnaire, 'Who relies on you for support (practically and emotionally) in a caring role on a regular basis? (don't include support that you provide solely in paid work or as a volunteer in a support group or network)'. It was asked that this question be cross-tabulated against respondents' age, gender, sexual orientation and the area of Brighton & Hove they lived in, in order to help identify unpaid LGBT carers. See the appendix on p.18 for more information.

In order to address this question, the Count Me In Too data was explored but Q.58, the question in the survey that directly related to carers, was found not to be robust enough to

provide this data. While responding 'yes' to this directed to a following question as an LGBT carer, discussion with the Health analysis group suggested that the caring relationships identified do not correspond to the category 'carer' as used by services. While it gave extensive insights into how LGBT people reported they received and acted in supportive roles for each other, it clearly went beyond what could be defined as 'carers'.

Consequently, and after consultation with the member of staff from the Carer's Centre, work was undertaken to address other literatures in this area, in order to help inform the work of the Carers' Centre in Brighton & Hove. 5 data bases were searched - these were the Applied Social Sciences Index and Abstracts (ASSIA), the International Bibliography of the Social Sciences (IBSS), Social Care Online, the ISI Web of Knowledge and Zetoc (the British Library's electronic table of contents). Specific search terms and in various combinations were used. These included 'LGBT', 'LGB', 'lesbian', 'gay', 'bi/bisexual', 'trans/transgender/transsexual', 'homosexual', 'queer', 'sexuality', 'care/carer/caring/carework/caregiver'.

1.4 Summary of research located

29 potentially relevant research studies were located based on their specific focus on LGBT people and/or distinguishing respondents by sexual orientation or LGBT-identities; their focus on unpaid or 'casual' care work; and by examining the varied uses of the terms 'care' and 'carer' in research. These studies generally took the form of articles detailing the background, methodology, methods, findings and findings analysis of a specific piece of evidence-based social research, or occasionally taking the form of a literature review and discussion. These studies have all been peer-reviewed and published in books or periodicals. This review sought to filter out research studies that were not consistent with the understanding of the term 'carer' within the context of local services, as occurred when the question (58) was taken to define 'carer' in the Count Me In Too questionnaire. In this latter approach the use of the term 'carer' proved useful – as a practice-based identity or role it suggests a certain level of dedication and investment of time and energy that it seemed matched the proposed focus of the research. The term 'carer' is used in almost all of the research detailed in this report. Some pieces discuss problems with 'carer' as an identity (McCann & Wadsworth 1992, Hines 2007,) or as a fixed definition (Hines 2007), and the wide variety of roles covered by 'carers' in the research detailed would seem to justify this. However, care was taken to filter out research involving only paid caring, and research in which paid and unpaid/voluntary caring were not sufficiently distinguishable.

The studies found were mainly carried out in North America during the 90s, and the majority focus on gay male carers (most frequently close friends, partners or lovers) of people living with HIV/AIDS. Some key publications include:

- Fredriksen's 'Family Caregiving Responsibilities Among Lesbians and Gay Men' - this study is widely cited and dispels the notion that lesbians and gay men have no familial caring responsibilities (Fredriksen 1999);

- Aronson's 'Lesbians Giving and Receiving Care'; - one of the few works which engages specifically with lesbian communities (as opposed to LGBT or gay communities). This study demonstrates that lesbian carers have distinct lives and needs and, extrapolating from this, that gay male, bi and trans carers will have similarly distinct lives and needs too (Aronson 1998);

- the works of Irving, Turner, Wight and Pearlin on the carers of those living with HIV/AIDS – these are some of the most widely-cited writers and they bring out many similar themes in their research including the 'dual stigma' of gay identities and HIV/AIDS and the substantial service needs of gay men caring for partners with HIV/AIDS (Irving et al 1995, Pearlin et al 1997, Turner et al 1998, Wight 2000).

Regarding the research methodologies used in these studies, there is a clear divide between the mostly quantitative, statistical research involving LGBT carers and HIV/AIDS, and the mostly qualitative, interview-based research involving other LGBT carers. In general, however, there is a noticeable paucity of research on LGBT carers. Particular gaps that can be identified are:

- a lack of studies outside of North America (urban California in particular);

- an absence of research that addresses carers who are not involved in caring for someone living with HIV/AIDS;

- a shortage of research on gay men that does not focus on the young to middle-aged;

- while there was some research exclusive to gay men, to lesbians and to trans people, no research was found that dealt exclusively with bi carers – in fact many studies, in their specific focus on gay men and/or lesbians, exclude bi people from their research.

The paucity of research surrounding LGBT carers is mentioned in a number of different articles (Fredriksen 1999, Manthorpe 2003, Hines 2007, Munro & Edward 2008). Some researchers have suggested that further investigation should be carried out in the following particular areas in order to augment the existing research in them:

- Caring in lesbian relationships (Aronson 1998, Manthorpe 2003)

- Care work and LGBT seniors (Brotman et al 2007)

- Gay grandparents' relationships with children and grandchildren (Orel 2006)

- Combining social support with relationship maintenance to help same-sex couples coping with HIV/AIDS (Haas 2002)

2 - Findings

2.1 Introduction

This report focuses on the key findings from the literature searching undertaken in November and December 2009. Based on the most common overarching themes that emerged from the literature, these key findings, are organised into four broad groupings. For each grouping some key points (and some specific examples for each) are given:

- **Identities and Being Out** – research findings that explore how open LGBT carers are about their sexual/gender identities and how this impacts on their lives/care giving;

- **Social Networks and LGBT Communities** – research findings that deal with the linking of LGBT carers to communities and networks of shared identities or experiences;

- **Families** – these research findings deal with the families of LGBT people and their connection with care work;

- **Carers and HIV/AIDS** – the grouping with the largest number of relevant research studies, which collates the research focused on LGBT carers with HIV/AIDS, and LGBT carers who care for those with HIV/AIDS.

2.2 Identities and Being Out

Research with carers reports that being 'out' about a carer's sexual identity is beneficial for a person's wellbeing, while not being out can increase stress for carers. Some choose not to be out so as to gain legitimacy as a carer, to ward off bad reactions and to protect those they are caring for (Mullan 1998, Aronson 1998, Fredriksen 1999, Orel 2006, Brotman et al 2007). Evidence suggests that the oldest and the youngest carers may be the least likely to be out (Mullan 1998, Orel 2006).

- In Aronson's study of 15 lesbians with experiences of giving/receiving care she found that participants regularly spoke to her in interviews about issues of being out as a lesbian carer, and the impact of not being out on capacity, security and in one case even access to benefits (Aronson 2006).

- Mullan, studying data from the 1992 UCSF AIDS Care Study in urban California, notes that the degree of 'outness' of participants is directly related to caregivers' wellbeing and sense of caregiving competence (Mullan 1998).

- In her study of 16 lesbian and bisexual grandmothers in the USA, Orel notes that all participants brought up, and discussed, the psychological importance of self-identifying as lesbian or bisexual. Additionally all of those who were out to their grandchildren (75% of the sample) said that this openness was a key factor in a good relationship with their grandchildren (Orel 2006).

- In a research study with 17 caregivers of gay and lesbian seniors in Canada, Brotman et al found that lesbian and gay participants, both carers and those in care, had a greater ability to advocate for services when they were out. (Brotman et al 2007).

- Fredriksen's 1999 research on family caregiving amongst lesbians and gay men examined the questionnaire responses of 1,466 respondents from across the USA. The majority of lesbian and gay male parents were revealed to be out in at least some

settings, however these numbers were still low. Only around 51% were out to all of their co-workers, 58% to medical service providers and 34% to their neighbours. 35% were not out to any personnel at their children's school (Fredriksen 1999).

- The oldest and youngest carers seem the least likely to be out about their sexuality (Orel 2006). Orel does not define these age categories, but further evidence is found by Mullan - analysing the results of the UCSF AIDS Care Study, he notes a clear relationship between age and degree of outness, with the oldest (aged 50+) and youngest (aged 20-29) gay male caregivers being the least likely to be out (Mullan 1998).

2.3 Social Networks and LGBT Communities

Involvement in the gay community may be an important determinant of support for gay caregivers (Turner et al 1998).However not all carers draw on this support, and some – such as parents – can be isolated from them, as Hicks' research in the UK found, drawing on data from his interviews with 40 gay and lesbian carers and thirty social workers (Hicks 2006). Relying on caring/support networks to based on shared identities such as 'lesbian', 'gay', 'bi' and 'trans' to 'pick up the slack' can be problematic due to internal differences between those defined as within the LGBT collective (Aronson 1998, Cant 2004, Hines 2007).

- In their 1998 US study of social support for caregivers of people with AIDS, involving 642 participants from urban California, Turner et al found the factor of 'gay participation' a significant predictor (p< .01) of emotional support for gay carers. The writers defined 'gay participation' as 'participation in gay organisations and activities', including the likelihood that respondents would 'frequent gay establishments, such as bars, restaurants, theatres, gyms' or 'read gay oriented newspapers, books, or magazines' (Turner et al 1998).

- In a 2007 study of caring in transgender communities and networks in the UK, Hines notes that trans care networks are seen to 'fill the gap' left by official support services. However, she also found that the differing approaches to trans identities by those within these networks leads to very different levels of commitment to care and engagement/disengagement at different times. This highlights problems when imagining 'community'-based care centred around on shared identities (Hines 2007).

- In Hines' research, trans carers suggested that educating people about trans issues and 'giving something back' should both be considered key ethics of care, expanding the notion of what counts as care work. This may also suggest that different sectors of the LGBT collective conceptualise 'care' in different ways (Hines 2007).

- Cant's 2004 study of three social networks for gay men in London (including one for the carers of gay men and lesbians) demonstrated that these networks' capacities were highly dependent on the social circumstances of participants and could easily collapse. Cant suggests that instead of relying on these networks, statutory services should offer material support to them (Cant 2004).

- In the research there were differences between lesbian carers that were frequently made 'invisible'. For example, in Aronson's research various participants suggested those with certain 'politicised' illnesses such as breast cancer could find it easier to rally lesbian support than those with chronic fatigue syndrome or mental health problems. Class and access to resources also influenced lesbian care networks (Aronson 1998). Further research is needed into how similar internal differences in other aspects of LGBT communities and networks that addressed how specific illnesses or social differences may impact on LGBT carers' lives.

2.4 **Families**

Contrary to historical discourses around LGBT people and families, the research showed that LGBT people do indeed have families and responsibilities of care to their families. LGBT parents said that they could be excluded from 'mainstream' LGBT scenes and networks, though they in turn were found to sometimes marginalise or devalue the lives of non-parent LGBT people. Carers most often found peer networks to be the best form of support, but the research also showed considerable support from their biological families, suggesting that this may be a neglected area of study.

Familial caring relationships

Research on familial caring relationships in particular has historically been highly heteronormative, assuming and tacitly encouraging heterosexuality (particularly as it relates to kinship and reproduction) while making homosexuality invisible and/or devalued (Mullan 1998, Aronson 1998, Turner et al 1998, Manthrope 2003, Orel 2006, Hicks 2006, Brotman et al 2007). Yet, contrary to popular discourse lesbians and gay men can have extensive familial caring duties.

- Orel estimates that in the USA there are an around 3 million gay and lesbian parents, leading to a conservative estimate of 1-2 million gay and lesbian grandparents in the near future (Orel 2006).

- Fredriksen reports that a third of gay and lesbian respondents in her study – recruited from a national US listing of those willing to participate in social research - were providing some kind of familial caring assistance (Fredriksen 1999).

Parenting

Gay and lesbian parents can be excluded from 'mainstream' LGBT scenes and networks; however Hicks' research reveals that they can also speak and act in ways that can marginalise non-parents, particularly by riffing off of broad societal themes such as ir/responsibility (Hicks 2006).

Partners, peers and familial support for carers

Familial responsibilities – such as to children or grandchildren – can result in stress and/or conflict between carers and their partners. Additionally, while peer support is usually reported to be the best or most helpful form of support for LGBT carers, the research found that LGBT carers' biological families are by no means necessarily hostile and that they may be a neglected source of support.

- The partners of those carers with familial responsibilities can become sites of conflict – many partnered participants in Orel's study (56% of the sample) of lesbian and bisexual grandmothers were jealous of their partners' lack of responsibility; others were often angered by their lack of interest in their grandchildren, leading to a stressed relationship (Orel 2006).

- Peer support is usually rated as the 'best' or 'most helpful' form of care assistance, with assistance from biological families the least helpful (Rolland 1994, Turner et al 1998). Members of biological families are also considerably less likely to help and support gay male carers of people with AIDS/HIV than are friends and peers. However, they remain a source of support for them and for other LGBT carers - not all LGBT carers are excluded by their families (Irving et al 1995, Turner et al 1998, Mullan 1998, Stajduhar 1998, Fredriksen 1999, Manthorpe 2003, Munro & Edward 2008).

- In Turner et al's 1998 California study, carers' contact with their biological family had an independent positive effect (p< .01) on the emotional support for carers of those with AIDS, albeit a weaker one than contact with friends or the gay community (Turner et al 1998).

- In his 2002 American study of 20 gay male couples living with HIV, Haas found that gay male couples in which one partner cared for another with HIV also frequently reported moderate to high levels of support from biological families, suggesting this source of support should not be discounted (Haas 2002).

- In a review of research on carers of those with HIV/AIDS, Mullan lists several studies including the UCSF AIDS Care Study that demonstrate that gay men most often choose gay male peers for support but also regularly turn to family relatives (Mullan 1998).

- Irving, Bor and Catalan's 1995 pilot study on the lovers and partners of gay men with AIDS, with 38 London-based respondents, found that while informal support was most commonly provided by friends (100%), the numbers reporting informal support from relatives or family members (29%) were not insignificant (Irving et al 1995).

- Fredriksen's research showed that 93% of her respondents had at least some supportive biological family members (Fredriksen 1999).

- For findings about partners and relationships more specific to HIV/AIDS-related care, see 'Importance of partnership and intimate relationships' under section 2.5.

2.5 Carers and HIV/AIDS

Most of the research carried out with/on LGBT carers is related to HIV/AIDS, and specifically the gay male carers of those with HIV/AIDS. Whilst much of this is specific to this context, there are areas that may be applicable elsewhere. The research revealed that LGBT carers with HIV/AIDS, or who care for a person with HIV/AIDS, can suffer a dual stigma from their sexual orientation and the stigma of the illness. This can have severe impacts on the mental health and wellbeing of carers. The service needs of these carers are not always met, though some carers actively chose not to use certain services for a number of reasons. As with non-HIV/AIDS-related research, this research showed that loving, intimate relationships are important for these carers' sense of mental wellbeing. Some research also suggested that religion and/or spirituality had increased importance for carers with HIV/AIDS. Finally, there was some evidence to show that the issues prompting thoughts of suicide are different for HIV- and HIV+ caregivers.

Stigma and Stress

Research in the area of caring and HIV/AIDS shows that there is often a dual stigma is attached to LGBT people with HIV/AIDS and those caring for them - namely, that there is the stigma of the illness, and the stigma of their sexuality. Both may work separately and together to increase stress reactions for carers (McCann 1992, Irving et al 1995, Gray & Hedge 1999, Wight 2000, Remien et al 2003, Munro & Edward 2008).

- Reynolds and Alonzo, studying 20 participants in the urban mid-west of the USA, noted that the lack of an accepted grieving role for male partners caring for men with HIV/AIDS was considered by some participants to intensify the stress of bereavement – this is particularly problematic because deaths and bereavements are frequently outcomes in HIV/AIDS caring relationships (Reynolds & Alonzo 1998).

- The 1999 British study by Gray and Hedge examined questionnaire responses by 35 gay men who cared for a partner with HIV. Using the Hospital Anxiety & Depression (HADS) anxiety scale, they found that 43% scored in the 'probable psychiatric disorder' range. Using the HADS depression scale 3% scored in the 'probable psychiatric disorder' range while 20% scored in the 'possible psychiatric disorder' range. These figures were found to be similar to those in previous studies and are considerably higher than figures for the general population (Gray & Hedge 1999)

- The 1995 research by Irving, Bor and Catalan revealed that a high percentage of the sample (74%) reported mental health problems and that 66% were possible or probable psychiatric cases according to the strictest criteria defined in the General Health Questionnaire which this research analyses (Irving et al 1995).

Service needs

HIV/AIDS caregivers have substantial service needs and these are not always met (McCann 1992, Irving et al 1995). There are substantial service needs even when people with HIV/AIDS have a caregiver. However some research found that people sometimes choose not to use services, for a variety of reasons including being too tired, not knowing where to go and not wanting to involve outsiders (McCann 1992, Irving et al 1995).

- In a study of 472 AIDS caregivers in urban California, Leblanc, Aneshensel and Wight found that gay male caregivers for people with HIV/AIDS demonstrated higher rates of psychotherapy use than the general population – 46% of their sample examined over time (n. 267) had used psychotherapy at some point during the data collection. Key stressors leading to psychotherapy were not care-related, but rather related to health, relationship status and living situation (Leblanc et al 1995).

- In Irving, Bor and Catalan's 1995 research only 37% of lovers and partners caring for partners with AIDS reported receiving formal support. Of those who did receive support, 39% were dissatisfied with it. (Irving et al 1995).

- McCann and Wadsworth's 1992 research on informal carers of gay men with HIV was based in London and involved 265 participants, the majority of whom were male and close friends or partners of the person cared for. The research is unusual for HIV/AIDS research in that it is qualitative rather than quantitative, and it found that almost 30% of carers said they would have liked more support but had not received it (McCann & Wadsworth 1992).

Importance of partnership and intimate relationships

For HIV/AIDS caregivers, living with one's partner in a loving, emotionally intimate and sexually satisfying relationship is important and can impact on the stress of the care work (Leblanc et al 1995, Pearlin et al 1997, Remien et al 2003).

- Pearlin, Aneshensel and Leblanc carried out research on 472 caregivers of people with AIDS in urban California. Their 1997 study shows that being the lover and long-term caregiver of a person with AIDS acts to diminish their work stresses and strains (Pearlin et al 1997).

- In Remien, Wagner, Dolezal and Carballo-Dieguez's 2003 study they looked at around 200 couples living with HIV/AIDS in New York. The findings reveal that higher levels of psychological distress correlated with, amongst other factors, participants' feelings of a poor relationship and less sexual satisfaction (Remien et al 2003).

- For findings about partners and relationships not specific to HIV/AIDS-related care, see 'Partners, peers and familial support for carers' under section 2.4.

Religion and Spirituality

HIV+ carers of those with HIV/AIDS were more likely to express religiosity/spirituality than HIV- carers, suggesting that existential concerns should not be dismissed (Folkman et al 1994, Cadell 2007).

- In a 1994 study in San Francisco, Folkman, Chesney, Cooke, Boccellari and Collette looked at a sample of 314 gay or bisexual men who were either living with HIV or caring for them. They found that caregivers who were living with HIV were more likely to be religious than those who were not (Folkman et al 1994).

- Cadell's Canadian study of HIV caregivers involved 15 participants, and they demonstrated a sense of connection between support, coping and religion/spirituality (Cadell 2007).

Suicide and Suicidal Thoughts

Rosengard and Folkman's 1997 Californian study looked at suicidal thoughts in 253 gay and bisexual male partners of men with AIDS. 55% reported thoughts of suicide at some point. Although they were not more likely to think of suicide than HIV- caregivers, there was evidence that there are different factors influencing thoughts of suicide for HIV+ caregivers compared to HIV- caregivers (Rosengard & Folkman 1997).

3 - Conclusions

3.1 Paucity of research

Using literature searching to address the question about LGBT carers, this research found a distinct paucity of research information about LGBT-related carework and LGBT carers, other than in the area of HIV/AIDS carework (primarily involving gay men and most frequently situated in urban California). The research studies identified key issues for LGBT carers and suggested that further research should be carried out into almost every aspect of LGBT carers' lives.

3.2 Identities and Being Out

The research unanimously found that being open and out about LGBT identities is important not only for carers' sense of wellbeing but also their ability to advocate for services. However, the research indicates that there may be reasons why LGBT carers choose not to be out.

3.3 Social Networks and LGBT Communities

Networks and communities can be important sources of emotional and instrumental support for LGBT carers. However, internal differences mean that these networks cannot just be relied upon by all LGBT carers, and additionally there may be unequal access to the networks' resources.

3.4 Families

The issue of family was a recurring one in the research, with two main strands: firstly, that LGBT carers' biological families are by no means necessarily hostile and that they may be a source of support neglected by researchers; secondly, that the concept of 'family' often excludes LGBT people, despite the fact that they may have extensive familial responsibilities to children, grandchildren, partners and so on.

3.5 Carers and HIV/AIDS

Although there is a lot of available research on HIV/AIDS carers it has a tendency to be focused on the USA, and Los Angeles and San Francisco in particular. Additional research into HIV/AIDS carework might benefit from further studies in a wider variety of locations. The 'dual stigma' of an LGBT identity and HIV/AIDS was raised by several pieces of research, which can work in tandem to negatively affect the lives of the carers of those living with HIV/AIDS. Other research revealed the importance of a loving, emotionally intimate and sexually satisfying relationship for LGBT HIV/AIDS carers and those they care for. Finally, some of this research explored, albeit briefly, the role of religion and spirituality – this seems to have been neglected in some other studies into LGBT carers, and while the evidence surrounding this is slight at the moment it may be a useful area for future work.

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