First person narratives around sexuality in residential healthcare settings: A meta-ethnographic synthesis

Anna Hooper[a], Danielle De Boos[a], Roshan das Nair[a], Nima Moghaddam[b]

[a] Division of Psychiatry and Applied Psychology, The University of Nottingham, UK

[b]Clinical Psychology, University of Lincoln, UK

Correspondence concerning this paper should be addressed to the last author: Nima Moghaddam, Research Clinical Psychologist. University of Lincoln, Clinical Psychology, Bridge House, Brayford Pool, Lincoln, UK, LN6 7TS.

Email: nmoghaddam@lincoln.ac.uk / Phone: (+44)1522 837733

First person narratives around sexuality in residential healthcare settings: A meta-ethnographic synthesis

Abstract

Purpose. *The aim of this review is to identify, critically appraise and synthesise existing literature exploring adults' narratives around sexuality within residential healthcare settings from a first-person perspective.*

Method. *A systematic literature review was undertaken. Six databases were searched. A meta-ethnographic approach was used to synthesise studies' findings.*

Results. *Thirteen studies using qualitative methodology that met the inclusion criteria were identified. The synthesis revealed six key themes: how service-users define sexuality, sexuality as something not to be discussed ('privates are private'), sexuality as a separate aspect of the self ('sectionality'), hopes and fears for the future, the impact of the environment ('physicality of being physical'), and adapted sexuality. The studies included were of varying quality.*

Conclusions. *Sexuality remains an important aspect for many residents, yet is rarely noted or discussed with them by healthcare staff. The residential healthcare environment presents implicit and explicit barriers to sexuality expression, causing residents to adapt how they experience their sexuality. Findings from this review highlight the importance of considering service-users' perspectives, and the need for open communication between residents and practitioners to facilitate care-provision that acknowledges the barriers of the environment on sexuality and considers the person beyond the presenting illness.*

Keywords: *Sexuality, Residential Healthcare, Meta-synthesis, Meta-ethnography, Qualitative Research*

Introduction

Sexuality

Sexuality is an important part of self-identity (Balen & Crawshaw, 2006). It encompasses intimacy, gender identities and roles, sexual orientation, eroticism, pleasure, reproduction and intercourse, and is shaped by the interaction of a number of components including biological, psychological, social, economic, political, cultural, religious and spiritual factors, (World Health Organization, [WHO] 2006). Balami defines sexuality as "a process of integrating emotional, somatic, and intellectual and social aspects in ways that enhance one's own self" (Balami, 2012, p.267). The WHO recognises sexuality as being integral to wellbeing and advocates that "health programme managers, policy-makers and care providers need to understand and promote the potentially positive role sexuality can play in people's lives" (WHO, 2006, p.1). Sexuality has been noted as an important factor in relation to many presenting concerns in clinical practice, such as self-identity, self-esteem, social relationships, social engagement, mental health problems including depression and anxiety, and quality of life (Barnard, 2009; Buffington, Luibhéid, & Guy, 2013; Burri, Spector, & Rahman, 2012; Heath & White, 2002; Langer, 2009; Mayers, Heller, & Heller, 2003; Pasko, 2010; Stevenson, 2010). Current literature increasingly acknowledges the important influence sexuality has with regards to individual wellbeing, and it is becoming widely-recognised as an important issue for the healthcare agenda.

Demand and residential healthcare services

As a result of changing population demographics, the number of individuals with long-term conditions and requiring care is increasing (HM Government, 2007), leaving a higher demand for healthcare services for patients. Admissions to healthcare settings are likely to increase in

frequency and duration, and many people may require long-term and residential healthcare. The ageing population is putting pressures on services; the number of care homes in the UK will need to increase by 140% over the next 50 years to keep pace with demographic pressures (Wittenberg, Comas-Herrera, Pickard, & Hancock, 2004). The Social Care Institute for Excellence (2009) advocate implementing person- and relationship-centred care in care homes, promoting individual identity and independence as a key to wellbeing. Sexuality is an integral component of the self; therefore it is logical that in order to provide recommended standards of care to the increasing numbers of service-users, residential healthcare practitioners must consider how individuals experience their sexuality when taking on the 'resident' role.

Sexuality and the residential healthcare environment

Existing research around sexuality is predominantly empirical in nature and the majority of current qualitative research around sexuality and residential healthcare has focussed heavily on the views of practitioners. For example, Bouman, Arcelus and Benbow (2007) researched attitudes of nursing staff of residential and nursing homes towards residents' sexuality. They identified some moderating factors which may predict negative and restrictive attitudes of staff, such as staff's age and number of years of experience. Research into nurses' views of discussing sexuality with their cancer patients revealed that they conceived patients' need of support regarding sexuality as being low during the care trajectory, and nurses' attitudes, knowledge and skills, and conditions in the ward environment prevented them from initiating discussions about sexuality (Olsson, Berglund, Larsson, & Athlin, 2012). This literature, whilst offering insightful accounts of how services engage with their patients' sexualities, fails to explore sexuality from the perspective of those being studied.

To explore the first-person perspectives of sexuality experiences of those residing in healthcare settings, we undertook a review of the existing literature using meta-ethnography. The overall aim of this review was to respond to the question 'how do individuals understand and experience their sexuality as residents[1] of healthcare settings?' Qualitative research aims to provide an in-depth understanding of processes, allowing the researcher to explore meaning of experiences in context (Harper & Thompson, 2012; Kopala & Suzuki, 1999; Spencer, Ritchie, Lewis, & Dillon, 2003). Meta-ethnography is an interpretive approach used to synthesise findings across qualitative studies to provide a higher level of analysis and generate new research questions (Atkins et al., 2008). By synthesising qualitative research, it is anticipated that the review will contribute to the scant and often disparate literature on sexuality and residential healthcare services, offering a much needed foundation from which to consider the needs of adults in healthcare settings. For the purposes of this review, 'residential healthcare' refers to any setting where an individual resides on either a temporary or permanent basis in order for the service to cater to their health, and may include: hospitals (acute, general and psychiatric), care homes, hospices, and nursing homes.

Methods

Searching

A systematic literature search was conducted (search concluded 19/09/2015) using six electronic databases: PsycINFO (1806-present), Medline (1946-present), Applied Social Sciences Index and Abstracts (1987-present), ProQuest Dissertations & Theses (1861-present), PsycARTICLES (1894-present) and Cumulative Index to Nursing and Allied Health

[1] 'Resident' and 'patient' are used interchangeably, and refer to persons admitted to residential healthcare services for treatment, e.g. residents of nursing and care homes, in-patients of psychiatric hospitals, and patients admitted to general hospitals for assessment/treatment.

Literature (1981-present). Please see Appendix A for a summary of the search strategy. These databases were selected because they collectively afford comprehensive coverage across a range of relevant healthcare disciplines and perspectives (medical, nursing, psychological, and social care); these databases have been commonly used in previous systematic reviews of qualitative healthcare research (Wright, Golder, & Lewis-Light, 2015). Subject headings that mapped onto search terms were selected where available. The publication type was not specified, although research was limited to those reporting on adult populations. Abstracts of papers were screened and the full-text articles were accessed of research that met the inclusion criteria. A manual review of references and citations of these articles was undertaken by the lead author (AH) once the database search was completed. The following inclusion criteria were applied:

(1) Research that considered individual experiences of sexuality in residential healthcare settings from a first-person perspective.
(2) Qualitative methods were used for analysis.
(3) Where researchers included views from those in residential healthcare and those who were not, the findings should have been distinguishable.
(4) Participants were aged 18 years and above.
(5) Publication was available in the English language.

Search terms

The search terms were developed through an iterative process. Initially, keywords cited by studies pertaining to qualitative sexuality research were trialled with the target databases. Based on the relevance of the search output, terms were either included or excluded. Additional terms used by some databases to refer to sexuality (such as “sex behaviour”) were incorporated as appropriate. The following search terms were included:

Sexual*, Sex* Behavio?r, Explorat*, Qualitative, Thematic Analysis, Discourse Analysis, Interpretive Phenomenological Analysis, Q methodology, Grounded Theory, Content Analysis, Conversation Analysis, Ethnograph*, Patient*, Resident*, Care Home, Nursing, Hospital.

Selection

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) was used as a framework for the process of article selection, as outlined in Figure 1. From the identified studies, duplicates were removed and abstracts of remaining articles were screened by AH against the inclusion criteria.

Data abstraction

Noblit and Hare's (1988) seven-phase meta-ethnographic approach informed the synthesis process. The studies were read, re-read, and the data was systematically extracted using a bespoke data extraction tool (see Appendix B) which included: the research question, location of study, participant details such as age and gender, recruitment method, data collection and analysis methods, validity of research findings, discussions and author conclusions. Three methods of synthesis were employed (Noblit & Hare, 1988): Reciprocal translations (translating concepts/themes/metaphors from one study across to another), refutational synthesis (taking account of the implied relationship between competing explanations), and lines-of-argument synthesis (reflecting on the synthesised information to make inferences about the 'whole').

Quality appraisal

With regards to meta-ethnography, the notion of quality appraisal remains an area of debate as some suggest the worth of studies may be determined by the process of achieving a synthesis (Hunter, Schmidt, & Jackson, 1982; Noblit & Hare, 1988). Research has found that including studies deemed to have poorer quality is unlikely to have a distorting impact on synthesis (Campbell et al., 2011). Therefore, the quality of studies was assessed as an indication of the state of current literature and the quality of studies was not used to inform how information would be weighted during the synthesis.

Reflexivity

Meta-ethnography will invariably be a product of the synthesizer, as the analyst is always translating studies into their own world view (Noblit & Hare, 1988). Therefore, transparency regarding how the researcher's presence and positioning might have influenced the research process and findings is a key attribute for good quality qualitative research (Finlay, 2006). Acknowledging the influence of the researcher on the research findings enables the reader to challenge the researcher's interpretation and assess inductiveness of findings (Toye et al., 2013). The first author's interest in sexuality and residential healthcare developed as a result of observations as a staff member in a nursing home and as a family member with a loved one in hospital. AH had noticed how the family member inhibited their usual display of affection when in the hospital, at a time when perhaps physical closeness with others may have brought them the most comfort. As a staff member in a nursing home, AH observed the role of the resident was often confounded with vulnerability, causing some staff to interpret resident's sexuality as hazardous and aversive. This review developed from an interest in how the residential healthcare environment impacts on sexuality from a first-person perspective, holding the expectation that individuals' experiences would be qualitatively different as a patient/resident compared to when residing in non-healthcare settings. To

minimise the impact of expectations, during the synthesis attention was paid to refutational accounts and themes were intentionally well supported with excerpts from original studies - strategies intended to help the reader to judge the inductiveness of the synthesis (Toye et al., 2013).

Results

From the 1271 records identified from the electronic database search, 29 full-text articles were reviewed. Sixteen of these were excluded for not meeting the inclusion criteria: four articles were not primary research, two were not from a first-person perspective, in one article the first-person views were indistinguishable from a community sample, the full text was unavailable on two occasions (one was unavailable in English, the full text of the second was unobtainable via interlibrary loans), and seven articles referred to participants who were not in residential healthcare in accordance with the previously specified definition. The remaining thirteen articles were included for synthesis. The systemic processes of identifying literature returned relatively small numbers of papers that explored sexuality and residential healthcare from a first-person perspective, highlighting this as an under-researched area.

Figure 1

Findings were incorporated from thirteen papers with a total of 271 participants, of which 172 people offered first-person perspectives regarding sexuality in residential healthcare. Two papers by the same authors were based upon the same research data (Quinn & Happell, 2015a, 2015b). Participants' ages ranged from 18-101, although two papers did not specify the age range of participants beyond citing the average age (80 years; Frankowski & Clark,

2009) or age bracket (50-60 and 70+ years, Nay, 1992). Of those described, 48% of participants were male and 52% female. Four studies reported on participants' ethnicity (Brown, Reavey, Kanyeredzi, & Batty, 2014; Jenkins, Walker, Cohen, & Curry, 2010; McCann, 2000; Stein et al., 2010). Due to inconsistent reporting, overall participant demographics could not be summarised. Regarding data collection, one study utilised focus groups (Stein et al., 2010) and one study used a combination of observation and conversational interviews (Frankowski & Clark, 2009); the remaining studies collected data via semi-structured interviews. The method of analysis varied, although three studies did not specify their data analysis procedures (Frankowski & Clark, 2009; Nay, 1992; Röndahl, Innala, & Carlsson, 2006). Whilst all studies reported aims relating to individuals' experiences of sexuality, research questions varied. The characteristics of included studies have been outlined in Table 2.

Table 2

Quality appraisal

Utilising robust quality markers to appraise qualitative research is essential for the credibility of meta-synthesis reviews (Walsh & Downe, 2005). Due to the varying approaches to qualitative research, a single-set of quality markers cannot be established (Spencer et al., 2003). This review utilised the Critical Appraisal Skills Programme ([CASP] Public Health Resource Unit, 2013) as a framework to evaluate the methodological quality of the studies selected for inclusion. The studies were reviewed on the basis of what was cited by the author(s) in the papers, which may not be an accurate representation of study procedures per se.

Table 3

The quality appraisal was undertaken by AH and a second author, and the studies were judged as varying in quality with relation to the appraisal markers. We arrived at slightly varying scores on some CASP criteria because of the ambiguous reporting by the papers authors and the subjective nature of the CASP. Discrepancies in CASP scores were due to wavering between 'unclear' and 'met/unmet' judgements. As we were unable to reach an agreement on all CASP criteria, where disagreements existed they have been reported in Table 3.

All studies were deemed to have a research question compatible with qualitative methodology and drew conceivable conclusions from their data. Two studies (Frankowski & Clark, 2009; Nay, 1992) identified research questions post-data collection; understanding sexuality experiences was not the primary question asked of the data in these studies.

Jootun, McGhee, and Marland (2009) argue that the inclusion of a reflexive account should be part of qualitative enquiry to increase the rigour of the research process and add credibility. Only one study (Lemieux, Kaiser, Pereira, & Meadows, 2004) described the researchers as having made their biases explicit during the data collection phase, however these were not expanded on within the text; none of the other studies reported on the relationship between the researcher(s) and participants. None of the studies reported their epistemological or ontological perspectives. A researcher's beliefs and values will influence decision making processes and the acquisition of knowledge (Keso, Lehtimäki, & Pietiläinen, 2009); the lack of transparency within the included articles limited the reviewers' abilities to draw conclusions about how the research findings were derived from the data. Of the thirteen

studies included, three studies used minimal direct quotes to support their findings (McCann, 2000; Nay, 1992; Stein et al., 2010) and one study did not cite any quotes from participants (Östman, 2008).

Interpretation of findings

Table 4

The meaning of sexuality

Five studies reported on their participants' views of what sexuality meant to them. The remaining studies did not report on how participants conceptualised 'sexuality'. Accounts identified were consistent in describing a broad definition of sexuality:

> *"touching, hugging, getting roses, comfort, warmth, being dressed up"* (Nay, 1992, p.314).
>
> *"kissing, cuddling, touching", "feeling wanted"* (McCann, 2000, p.136).
>
> *"it's a broad, broad spectrum of feelings … closeness", "it's an eye across the room; it's a holding of hands"* (Lemieux et al., 2004, p.632)
>
> *"You don't have to have intercourse but you can have a cuddle."* (Bauer et al, 2013, p.301).

Frankowski and Clark (2009) revealed that common forms of sexuality expression included intimate touch, hand holding, and other less physically intense expressions. The studies were consistent in suggesting that patients viewed sexuality as being multi-faceted and individualised, and something which went beyond the physical act of sex. Patients' definitions of sexuality were consistent with WHO's (2006) definition. Sexuality was

described by participants as including subtle aspects which may not be recognised by quantitative accounts of sexuality due to their subjective nature (for example, ‘an eye across the room’). Sexuality remained an important aspect of the self and a concern for patients.

Privates are private

“..But deeper things, you can’t talk to [staff] about. I’ve tried and they just go back to their checklist” (Brown et al., 2014, p.247)

Both reciprocal and refutational translation identified the theme of sexuality being something taboo or not openly discussed between patients and staff, and this was referenced within nine of the studies. Three studies offered an account of participants perceiving staff as unwilling to engage with discussions around sexuality (Brown et al., 2014; Lemieux et al., 2004; Östman, 2008), suggesting that the approach of care staff moderated how sexuality was discussed. McCann (2000) reported that patients appeared reticent about approaching staff to talk about sexually-related issues. The authors of the two studies solely recruiting gay and lesbian participants described residents as experiencing discomfort and lacking in confidence to initiate conversations about sexuality. These participants reported feeling afraid to discuss their sexuality due to anticipated rejection from staff:

> *“I’m afraid of the people I need the most”* (Stein et al., 2010, p.430).
>
> *“Rather than take a chance, I just don’t tell [staff or residents] anything.”* (Jenkins et al., 2010, p.408).

Frankowski and Clark (2009) noted from their observations of multi-residential housing that the concept of sexual-orientation was never discussed. Villar, Celdrán, Fabà and Serrat (2014) noted that amongst participants there existed the belief that sexuality is socially and morally inappropriate in older age. Findings from Bauer et al. (2013) revealed participants’ belief that sexuality was a private matter for the individual:

> *"How we feel about each other is our own personal thing", "It's between me and that lady. It's private, like your thoughts."* (Bauer et al., 2013, p.302).

Despite the varying accounts, there was a strong discourse around sexuality not being spoken about within residential healthcare settings.

Sectionality

A number of the studies explicitly and implicitly described participants' accounts of feeling compartmentalised; with residents reporting feeling that staff and services viewed them almost as a series of identities which were unrelated and could be separated and addressed independently (for example, the *'patient being'* separated from the *'sexual being').* Many participants offered accounts of residential healthcare staff failing to consider the relevance of their sexuality within the treatment course:

> *"I mean it can be very confusing … to have a female come and give me an injection in my bum…"* (Brown et al., 2014, p.249).

> *"We asked the doctor and we asked the nurse if it was ok [to engage in sexual behaviour] because I was taking chemo. Never saw a doctor change to so many different colours of red in all your life, I think that we were the first person to ask that."* (Lemieux et al., 2004, p.633).

> *"Just because you've suddenly got old, you've still got the same feelings"* (Nay, 1992, p.313)

Östman (2008) concluded that sexuality received no attention in the treatment process for patients. These accounts suggested that participants felt residential healthcare staff did not consider sexuality as being a relevant aspect when providing healthcare services to patients.

One resident described a sense of loss associated with the separation of the 'patient' and the 'sexual being':

> *"there's no sex in [the other patients'] lives anymore at all… well that's over, that's another thing that's over with"* (Lemieux et al., 2004, p.632).

The impact of 'sectionality' was also noted by the two studies interviewing gay and lesbian participants; one study reported that informants described negative experiences related to a lack of open and direct communication:

> "*..if they are direct and talked to me about how I live … that would just show they care"* (Röndahl et al., 2006, p.377).

A different account suggested the anticipation of a decrease in quality of care if staff were to consider the person's sexuality:

> *"they're [care staff] from a different background, and I know that if they knew I was gay, my care would be worse"* (Stein et al., 2010, p.430).

Hopes and fears

"[intimacy] it's more important to me than basically anything in life" (Lemieux et al., 2004, p.632).

The theme of hopes and fears was identified through reciprocal and refutational translation. Eight stu dies made reference to the hopes and fears that participants had regarding their sexuality as patients in residential healthcare settings and for the future (Frankowski & Clark, 2009; Jenkins et al., 2010; Lemieux et al., 2004; McCann, 2000; Röndahl et al., 2006; Stein et al., 2010).

A number of accounts suggested that participants had fears about their sexuality and how it might impact on their care. Some spoke about the potential to be punished for expressing their sexuality within the residential healthcare setting:

> *"You've got sexual discrimination, you know. You have to be careful … there might be somebody who might say, 'oh look what he said to me' … and you'd get in trouble."* (Bauer et al., 2013, p.304)

> *"I was busted in the quiet room with this girl . . . staff walked past while she was giving me oral sex and . . . I lost all of my leaves for it"* (Quinn & Happell, 2015b, p.2272).

Some gay and lesbian participants harboured fears about disclosing their sexuality (Jenkins et al., 2010; Röndahl et al., 2006; Stein et al., 2010):

> *"if they could ask questions that make me feel comfortable telling them that I'm worried about how I'm going to be treated"* (Röndahl et al., 2006, p.377),

> *"It would only make matters worse for me if [staff or other residents] knew, and so I can't speak about my life at all, can I?"* (Stein et al., 2010, p.430).

Others expressed fears about how their treatment might impact on their sexual expression; one participant spoke about fears of being almost contaminated from chemotherapy and how this might affect their partner during intercourse:

> *"they're putting [chemotherapy] inside your body – that's pretty scary. So you know it's floating around in your body so it can be passed on"* (Lemieux, Kaiser, Pereira, & Meadows, 2004, p.632).

Another account described how one participant had fears about how the environment might impact on any potential relationship developed whilst a resident:

> *"We've been found not guilty due to mental impairment and . . . people have lost their families . . . lost everything over it. They come in here and find a beautiful relationship and wanna keep that, and that's going to get taken away from them as well? Like you are telling a human being not to fall in love. It's unhumane"* (Quinn & Happell, 2015a, p.125).

Four studies described participants as viewing their sexuality as important to them (Frankowski & Clark, 2009; Lemieux et al., 2004; McCann, 2000; Quinn & Happell, 2015a), and that they had aspirations for future intimate relationships with others:

> *"Yes I would like to meet someone", "I'd like to get married eventually"* (McCann, 2000, p.136)
>
> *"Would like to go and get one (laughs) where you go to a movie or to a dance club .. a companion"* (Frankowski & Clark, 2009, p.29)
>
> *"I'm thinking about getting out and um having a beautiful relationship in the future and having kids."* (Quinn & Happell, 2015a, p.125).

Physicality of being physical

Nine studies made reference to the restrictions of the residential healthcare environment and the impact that this had on how participants experienced their sexuality. Barriers to expressing sexuality included the notion of 'checks' from staff:

> *It's not my private home and there's no private space"* (Brown et al., 2014, p.250)
>
> *"Alright they knock but at the same time they're in already."* (Bauer et al., 2013, p.303)

the lack of opportunity for a partner (Frankowski & Clark, 2009; Nay, 1992), and a general discourse about how residential healthcare settings inhibited sexuality:

> *"While I was in the hospital … I did not show my intimacy … but once we got our private room, things changed."* (Lemieux, Kaiser, Pereira, & Meadows, 2004, p.633).
>
> *"It's difficult in hospital"* (McCann, 2000, p136)
>
> *"Your room is supposed to be your private space, but even there you can't be sure that nobody is going to come in."* (Villar at el., 2014, p.2522)

> *"Most people in a relationship get to have sex in the night time. This can never happen for us."* (Quinn & Happell, 2015a, p.125)
>
> *"We've tried to lie on the one (single) bed and there just isn't room."* (Bauer et al., 2013, p.303).

Whilst the majority of participants viewed the residential healthcare as negatively impacting on their sexuality expression, one participant spoke positively about the impact of the environment, describing how it enabled them to further consider relationships before sexual intimacy occurs:

> *"Patients should be cautious at first and see how they go with the relationship. How they go without a sexual relationship. It doesn't just have to be about sex when you get into a relationship."* (Quinn & Happell, 2015b, p.2272).

Adapted sexuality

The notion of adapted sexuality refers to how participants experience a change in sexuality, whether that is in how it is defined and understood, or how it is expressed and negotiated within the wider context of being a residential healthcare service-user.

> *"…I still can't feel human enough to be a sexual being in this environment"* (Brown et al., 2014, p.250)

Eight studies (Brown et al., 2014; Frankowski & Clark, 2009; Lemieux et al., 2004; Nay, 1992; Östman, 2008; Stein et al., 2010; Villar et al., 2014) described participants as having experienced an 'adapted' sexuality; their experiences of their sexuality had changed as a result of their ailment and/or the residential healthcare environment. The shift in how sexuality was conceptualised was described more concretely by participants in residential healthcare settings for physical health needs, for example, aging participants described a shift in associations with sexuality, from procreation and marriage, to intimacy, spirituality and

beauty, (Nay, 1992). Gay and lesbian participants within Stein and colleagues (2010) research described the notion of having to go 'back in the closet' when moving to residential healthcare settings. Östman (2008) found that side-effects of the medication prescribed also affected some of the respondents' experiences of sexuality. Participants' sexuality as a resident was described as being quantitatively and qualitatively different, causing them to adapt how they experienced their sexuality.

The 'adapted sexuality' experienced by the participants was not always acknowledged by the staff. A quote provided by Frankowski and Clark illustrates how staffs' preconceptions about how patients express sexuality may not be congruent with the individual experience:

> *"People think we screw. I get my morning kiss and my nighttime kiss, and that's all."* (2009, p.29).

Despite the expression of sexuality having altered, participant reports suggested that sexuality was no less of an important aspect of their self-identity:

> *"It's still important, but …the frequency probably is not the same anymore. Sometimes I'm too tired."* (Lemieux, Kaiser, Pereira, & Meadows, 2004, p.632).
>
> *"Just because we draw a pension and we're under the Mental Health Act doesn't mean that we don't have needs and wants for a relationship and sex."* (Quinn & Happell, 2015a, p.125).

Line of argument synthesis

A line of argument synthesis puts similarities and dissimilarities of studies into a new interpretive context (Noblit & Hare, 1988). The line of argument in this review represents a general consensus from the studies. The synthesis of the thirteen original papers revealed sexuality experiences were altered on the basis of the interaction between the restrictions and

permissions of the environment, the physical and mental impact of the illness/ailment that necessitated the person's residency in the healthcare setting, and the individual's pre-existing construction of sexuality. These interactions result in an adapted sexuality, influencing how individuals' construct their sexuality as a resident and how they express sexuality within the residential healthcare environment.

Figure 2

The key themes identified across the studies were interdependent. Experiencing an adapted sexuality in the residential healthcare setting brought about a number of hopes and fears for participants. Hopes and fears may be shaped by the milieu within the residential healthcare environment. Across the studies there was a strong narrative about sexuality being an aspect of the self that was not openly recognised nor discussed as part of patients' care, linked to the notion of 'sectionality' and staff viewing residents' heath needs as being independent and unrelated to sexuality. The amalgamation of contrasting accounts indicates reasons for the lack of dialogue about sexuality as being along a continuum, from participants not wishing to discuss sexuality ("won't talk") to wishing to discuss sexuality but these conversations not being initiated by staff, or staff perceived as non-recipient ("don't talk"). The individual's construction of what sexuality is, how this is incorporated in their sense of self, and the culture of the residential healthcare environment also seem to have an impact on how permissible it is for the individual to acknowledge the role of sexuality in their lives as a resident. The findings are unclear in concluding on how participants might appraise the changes they experience in sexuality as patients.

Figure 3

Discussion

It is clear from the literature that sexuality is strongly related to patient wellbeing and quality of life, and should be a noted component within residential healthcare provision. The findings of the synthesis highlighted differences between participants wishing to discuss sexuality versus how permissible this was perceived to be within the residential healthcare environment. This finding is in support of previous research which concluded that sexuality is not routinely discussed within healthcare environments (Dyer & das Nair, 2013). Research has suggested that healthcare practitioners also often express discomfort and uncertainty around initiating conversations about sexuality with their patients (Gamel, Davis, & Hengeveld, 1993; Garrett, 2014; Gott, Hinchliff, & Galena, 2004; Roach, 2004; Zeng, Liu, & Loke, 2012). The findings from our review suggest that discomfort and a lack of confidence are barriers to discussing sexuality experienced by both care staff and patients. Furthering practitioners' understanding around experiences from a first-person perspective may result in their increased confidence in understanding the role sexuality has for their patients, and help staff and patients work towards fostering an environment that is open about patient sexuality. To facilitate these discussions, it may help for staff to present as willing to engage with conversations about sexuality, communicating openness and acceptance. Gay and lesbian residents expressed higher levels of concern regarding discussing sexuality compared to heterosexual residents; environments that communicate acceptance of varied sexual orientations (e.g. through posters/leaflets) may serve to help alleviate residents' fears.

From the findings, it is clear that individuals in residential healthcare settings experience a change in their sexuality, whether that is related to how individuals define sexuality or as a result of the environmental influence on how they negotiate and express their sexuality. According to Kiecolt's (1994) theoretical model of self-identity and stress, a stressor may cause identity change depending on the following factors: identity-relevance of

the stressor, perceptions of responsibility of the stressor, awareness of/access to structural supports, the belief that one can effect self-change, the extent to which change benefits outweigh the costs, and social support for self-change. If we consider the residential healthcare setting and the individual's decline in health status as representing the stressor, it may be hypothesised that the change in self-identity occurs in instances where the previously listed circumstances are present. Kiecolt predicts that self-identity change will also become more likely when the stressor involves a person's roles. Individuals admitted to residential healthcare settings transition from the role of 'parent', 'partner', 'worker', to 'patient', and the relevance of sexuality may not be acknowledged within this new role. If we accept sexuality as an integral and significant aspect of the self, the identity-relevance of the stressor will be high (from a sexual being, to a non-sexual being). Gay and lesbian participants of studies described fear and inhibited sexuality in the residential healthcare settings, and 'hopes' were discussed by other participants as being in relation to sexuality expression outside of the healthcare setting. In both accounts, by accepting oneself as temporarily asexual, the patient is likely to experience more benefits than costs. On the basis of the findings, Kiecolt's theory appears to offer a sound explanation for how individuals may experience sexuality and self-identity change; 'adapted' sexuality arises from altered self-identity which comes about from a change in role and the environmental context that neither acknowledges nor facilitates individual sexuality. Encouraging open discussions about sexuality may serve to minimise the impact the residential healthcare setting can have, creating a milieu that promotes individual's self-identity beyond that of a patient to more broadly consider health and wellbeing in order to meet the needs of patients.

Across the findings, participants communicated that their experiences of sexuality were influenced by the physical environment of the residential healthcare setting, the approach of care staff, and the ailment that necessitated the patient's admission. Whilst this

review offered a descriptive account regarding the change in self-identity with relation to sexuality, a 'what' rather than a 'why' question was asked of the existing data. The review did not answer how participants appraised their 'adapted sexuality', and the impact of environment versus illness could not be disentangled. From the few studies selected for this review, it is evident that participants of different settings, cultures and sexual-orientations hold different narratives about their experiences of sexuality, which have been considered in light of each other to offer a general account of how sexuality may be experienced within residential healthcare settings. Humans are diverse and complex and cannot be understood as the sum of their parts, therefore extracting data on a single aspect of the self (sexuality) needs to take account of the other identities that contribute to the individuals overall sense of self. It is proposed that further research that seeks to explore the sexuality experiences of homogenous groups from a first-person perspective is required in order to more sensitively consider the influence of individuals' contexts on their sexuality experiences as patients. The review therefore highlights the need for further research in the area of residential healthcare and sexuality.

Limitations

The explanatory context of research is an important aspect to consider in the analysis and interpretation of qualitative data (Atkins et al., 2008). A potential limitation of the current review was that studies were geographically diverse, with data being derived from a number of international locations and residential healthcare settings and from participants of varying ages, ethnicities and religions. The participants sampled also had varying mental and physical health concerns, and ranged from having been hospitalised against their will to self-admissions. The heterogeneity of participants enabled the synthesis to consider a range of experiences; more broadly, inclusion of heterogeneous studies has been identified as

desirable and perhaps crucial for facilitating higher-order abstractions in meta-ethnography (Britten et al., 2002). However, the inability to determine the extent to which the individual experience may have changed since becoming a resident is a proposed limitation of the synthesis. To add clarity and further understanding in this area, we suggest that future research takes into account how a person constructs their sexuality pre- and post-admission to a residential healthcare setting, which may add further value to this area.

Due to the lack of transparency of some studies (owing to lack of reflexivity, or minimal use of original data to support findings), the influence and biases of the authors on the conclusions of their research could not be determined in all cases. A number of studies selected for the synthesis were purely descriptive in nature (versus interpretive), and in some cases differentiation between original material and interpretations made by researchers was unclear, especially where original quotes were not provided. With consideration to these two factors, the extent to which the interpretations generated from the synthesis are supported by primary data is unclear, questioning the extent to which the synthesis findings are consistent with participant narratives. Due to the limitations of existing literature around residential healthcare and sexuality, the present synthesis is not without its limitations.

Quality of the meta-ethnographic synthesis

To appraise the quality of this synthesis, the CASP (Public Health Resource Unit, 2010) checklist for systematic literature reviews was adapted for application to the present meta-synthesis; the adaptation included the supplement of transparency and reflexivity for precision of findings. The following broad domains have been considered to assess quality: Are the results of the review valid? What are the results? Will they help locally? Across these domains, our self-assessment indicated that the current review may have met 7 of the 8 applicable standards. We suggest that this review had a focussed (albeit broad) research

question and appropriate papers were sought. All identified relevant studies were included against specified criteria, and the quality of the studies was reviewed. Despite identified limitations, the review appears to offer a seemingly congruent account of sexuality from a first-person perspective; the synthesis offers relevant insights that go beyond the limitations of isolated studies, and concludes with statements pertaining to the clinical relevance of findings and future implications.

Conclusion

The review aimed to identify, critically appraise and synthesise qualitative research to further understanding of how adults experience their sexuality in residential healthcare settings. The review has highlighted some of the different ways in which individuals experience their sexuality in residential healthcare settings, contributing to recommendations for future research and practice. Chiefly, findings manifest a need for practitioners to provide openings for discussion of resident sexuality and other valued aspects of identity that may be threatened in the context of illness and the residential healthcare environment; such discussions would seem essential to facilitating truly person-centred care.

References

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Medical Research Methodology, 8,* 21. doi:10.1186/1471-2288-8-21

Balami, J. S. (2012). Ageing and sexuality: A neglected issue among care home residents. In N. E. Peterson & W. Campbell (Eds.), *Handbook on Sexuality*. New York: Nova Science Publishers, Inc.

Balen, R., & Crawshaw, M. (2006). *Sexuality and fertility issues in ill health and disability: From early adolescence to adulthood.* London: Jessica Kingsley Publishers.

Barnard, A. (2009). Lesbians' constructions of depression. *Health Care for Women International, 30*(5), 373–389.

Bauer, M., Fetherstonhaugh, D., Tarzia, L., Nay, R., Wellman, D., & Beattie, E. (2013). 'I always look under the bed for a man'. Needs and barriers to the expression of sexuality in residential aged care: the views of residents with and without dementia. *Psychology & Sexuality, 4*(3), 296-309.

Bouman, W. P., Arcelus, J., & Benbow, S. M. (2007). Nottingham study of sexuality and ageing (NoSSA II). Attitudes of care staff regarding sexuality and residents: A study in residential and nursing homes. *Sexual and Relationship Therapy, 22*(1), 45–61.

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy, 7*(4), 209-215.

Brown, S. D., Reavey, P., Kanyeredzi, A., & Batty, R. (2014). Transformations of self and sexuality: Psychologically modified experiences in the context of forensic mental health. *Health, 18*(3), 240–260. doi:10.1177/1363459313497606

Buffington, R. M., Luibhéid, E., & Guy, D. J. (2013). *A global history of sexuality: The modern era*. Oxford: Wiley.

Burri, A., Spector, T., & Rahman, Q. (2012). The etiological relationship between anxiety sensitivity, sexual distress, and female sexual dysfunction is partly genetically moderated. *The Journal of Sexual Medicine, 9*(7), 1887–1896.

Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L., Pope, C., & Donovan, J. (2011). Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment, 15*(43), 1–164. doi:10.3310/hta15430

Dyer, K., & das Nair, R. (2013). Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom. *Journal of Sexual Medicine, 10,* 2658–2670.

Finlay, L. (2006). “Rigour”, “ethical integrity” or “artistry”? Reflexively reviewing criteria for evaluating qualitative research. *British Journal of Occupational Therapy, 69*(7), 319–326.

Frankowski, A. C., & Clark, L. J. (2009). Sexuality and intimacy in assisted living: Residents’ perspectives and experiences. *Journal of NSRC, 6*(4), 25–37.

Gamel, C., Davis, B. D., & Hengeveld, M. (1993). Nurses’ provision of teaching and counselling on sexuality a review of the literature. *Journal of Advanced Nursing, 18*, 1219–1227.

Garrett, D. (2014). Intimacy for older people, *British Journal of Nursing*, *23*(6), 327–332.

Gott, M., Hinchliff, S., & Galena, E. (2004). General practitioner attitudes to discussing sexual health issues with older people. *Social Science & Medicine, 58*(11), 2093–2103.

Harper, D., & Thompson, A. R. (Eds.). (2012). *Qualitative research methods in mental health and psychotherapy*. Chichester: John Wiley & Sons Ltd.

Heath, H., & White, I. (2002). *The challenge of sexuality in health care.* London: Blackwell Science Ltd.

HM Government. (2007). *Putting people first: A shared vision and commitment to the transformation of adult social care.* Retrieved from http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

Hunter, J. F., Schmidt, F., & Jackson, G. (1982). *Meta analysis*. Newbury Park, CA: Sage.

Jenkins, D., Walker, C., Cohen, H., & Curry, L. (2010). A lesbian older adult managing identity disclosure: A case study. *Journal of Gerontological Social Work, 53*, 402–420.

Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard, 23*(23), 42–46. doi:10.7748/ns2009.02.23.23.42.c6800

Keso, H., Lehtimäki, H., & Pietiläinen, T. (2009). Engaging in reflexive acts - Sharing experiences on reflexivity in empirical qualitative research. *Tamara Journal, 7*(3), 51–70.

Kiecolt, K. J. (1994). Stress and the decision to change oneself: A theoretical model. *Social Psychology Quarterly*, *57*(1), 49–63.

Kopala, M., & Suzuki, L. A. (Eds.). (1999). *Using qualitative methods in psychology*. London: Sage Publications.

Langer, N. (2009). Late Life Love and Intimacy. *Educational Gerontology, 35*(8), 752–764.

Lemieux, L., Kaiser, S., Pereira, J., & Meadows, L. M. (2004). Sexuality in palliative care: patient perspectives. *Palliative Medicine, 18,* 630–637.

Mayers, K. S., Heller, D. K., & Heller, J. A. (2003). Damaged sexual self-esteem: A kid of disability. *Sexuality and Disability, 21*(4), 269–282.

McCann, E. (2000). The expression of sexuality in people with psychosis: breaking the taboos. *Journal of Advanced Nursing, 32(*1), 132–138.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine, 6*(7). doi:10.1371/journal.pmed.1000097

Nay, R. (1992). Sexuality and aged women in nursing homes. *Geriatric Nursing, 13*(6), 312–314.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies.* London: Sage Publications.

Olsson, C., Berglund, A.-L., Larsson, M., & Athlin, E. (2012). Patient's sexuality - a neglected area of cancer nursing? *European Journal of Oncology Nursing, 16*(4), 426–431.

Östman, M. (2008). Severe depression and relationships: the effect of mental illness on sexuality. *Sexual and Relationship Therapy, 23*(4), 355–363. doi:10.1080/14681990802419266

Pasko, L. (2010). Damaged daughters: The history of girls' sexuality and the juvenile justice system. *The Journal of Criminal Law and Criminology, 100*(3), 1099–1131.

Public Health Resource Unit. (2010). Critical Appraisal Skills Programme. Systematic Review Checklist. Retrieved from http://www.caspinternational.org/mod_product/uploads/CASP_Systematic_Review_Checklist_14.10.10.pdf

Public Health Resource Unit. (2013). Critical Appraisal Skills Programme. Qualitative Research Checklist. Retrieved from http://www.casp-uk.net/wp-content/uploads/2011/11/casp-qualitative-research-checklist-31.05.13.pdf

Quinn, C., & Happell, B. (2015a). Consumer sexual relationships in a forensic mental health hospital: Perceptions of nurses and consumers. *International Journal of Mental Health Nursing, 24,* 121-129.

Quinn, C., & Happell, B. (2015b). Sex on show. Issues of privacy and dignity in a forensic mental health hospital: Nurse and patient views. *Journal of Clinical Nursing, 24,* 2268-2276. doi:10.1111/jocn.12860

Roach, S. M. (2004). Sexual behaviour of nursing home residents: staff perceptions and responses. *Journal of Advanced Nursing, 48*(4), 371–9. doi:10.1111/j.1365-2648.2004.03206.x

Röndahl, G., Innala, S., & Carlsson, M. (2006). Heterosexual assumptions in verbal and non-verbal communication in nursing. *Journal of Advanced Nursing, 56*(4), 373–381.

Social Care Institute for Excellence. (2009). Personalisation briefing: Implications for residential care homes. Retrieved June 7, 2014, from http://www.scie.org.uk/publications/ataglance/ataglance17.asp

Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). *Quality in qualitative evaluation: A framework for assessing research evidence.* London. Retrieved from http://www.civilservice.gov.uk/wp-content/uploads/2011/09/a_quality_framework_tcm6-38740.pdf

Stein, G. L., Beckerman, N. L., & Sherman, P. A. (2010). Lesbian and gay elders and long-term care: Identifying the unique psychosocial perspectives and challenges. *Journal of Gerontological Social Work, 53*, 421–435.

Stevenson, C. (2010). Talking about sex. In C. Butler, A. O'Donovan, & E. Shaw (Eds.), *Sex, Sexuality and Therapeutic Practice* (pp. 31–54). Hove: Routledge.

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., Andrews, J., & Barker, K. (2013). "Trying to pin down jelly" - exploring intuitive processes in quality assessment for meta-ethnography. *BMC Medical Research Methodology, 13*, 46. doi:10.1186/1471-2288-13-46

Villar, F., Celdrán, M., Fabà, J., & Serrat, R. (2014). Barriers to sexual expression in residential aged care facilities (RACFs): comparisons of staff and residents' views. *Journal of Advanced Nursing, 70*(11), 2518-2527. doi:10.1111/jan.12398

Walsh, D., & Downe, S. (2005). Meta-synthesis method for qualitative research: a literature review. *Journal of Advanced Nursing, 50*(2), 204–211. doi:10.1111/j.1365-2648.2005.03380.x

Wittenberg, R., Comas-Herrera, A., Pickard, L., & Hancock, R. (2004). *Future demand for long-term care in the UK*. York: Joseph Rowntree Foundation.

World Health Organization. (2006). Defining sexual health. Retrieved May 16, 2014, from http://www.who.int/reproductivehealth/topics/gender_rights/defining_sexual_health.pdf?ua=1

Wright, K., Golder, S., & Lewis-Light, K. (2015). What value is the CINAHL database when searching for systematic reviews of qualitative studies? *Systematic Reviews, 4*(1), 1-8.

Zeng, Y. C., Liu, X., & Loke, A. Y. (2012). Addressing sexuality issues of women with gynaecological cancer: Chinese nurses' attitudes and practice. *Journal of Advanced Nursing, 68*(2), 280–292.

Appendix A

Summary of the search strategy

Overall search strategy: ‘Sexuality’, ‘Qualitative’ and ‘Residential care’

Cumulative Index to Nursing and Allied Health Literature

Search terms	
1	Sexuality (Subject heading)
2	"Sex* behavio?r".
3	1 or 2
4	Residential Facilities (Subject heading)
5	(inpatients or patient* or hospital* or "nursing home" or "care home" or resident).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
6	Inpatients or Rehabilitation Patients or Stroke Patients or Psychiatric Patients or Terminally Ill Patients or Nursing Home Patients or Aged, Hospitalized (Subject headings)
7	"Hospital*" OR "Nursing home" OR "Care home" OR "Resident*"
8	4 or 5 or 6 or 7
9	Qualitative studies (Subject heading)
10	qualitative or explora* or "thematic analysis" or "discourse analysis" or "grounded theory" or "interpretive phenomenological analysis" or "conversation analysis" or "content analysis" or ethnograph* or "Q method*"
10	9 or 10
11	3 or 8 or 10
11	6 and 9 and 10

PsycINFO

Search terms	
1	Sexuality (Subject heading)
2	"Sex* behavio?r".
3	Residential care institutions/ or Halfway houses/ or Hospitals/ or Nursing homes/ or Assisted living/ or Group homes/ or Psychiatric units/ or Retirement communities/ or Treatment facilities/ (Subject heading)
4	(inpatients or patient* or hospital* or "nursing home" or "care home" or resident).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
5	1 or 2
6	3 or 4
7	Qualitative research (Subject heading)
8	(qualitative or explora* or "thematic analysis" or "discourse analysis" or "grounded theory" or "interpretive phenomenological analysis" or "conversation analysis" or "content analysis" or ethnograph* or "Q method*").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
9	7 or 8
10	5 and 6 and 9
11	Limit 10 to Adulthood 18+

Medline

Search terms	
1	Sexuality (Subject heading)
2	"Sex* behavio?r".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
3	1 or 2
4	Residential Facilities (Subject heading)
5	Inpatients (Subject heading)
6	(inpatient* or patient* or hospital* or "nursing home" or "care home" or resident*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
7	4 or 5 or 6
8	Qualitative Research (Subject heading)
9	(qualitative or explora* or "thematic analysis" or "discourse analysis" or "grounded theory" or "interpretive phenomenological analysis" or "conversation analysis" or "content analysis" or ethnograph* or "Q method*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
10	8 or 9
11	3 and 7 and 10
12	Limit 11 to 19+ years

PsycARTICLES

Search terms	
1	(sexuality or "sex* behavio?r*").mp. [mp=title, abstract, full text, caption text]
2	("residential facilities" or "inpatient*" or "patient" or hospital* or "care home*" or domiciliary or "nursing home*" or resident*).mp. [mp=title, abstract, full text, caption text]
3	(qualitative or explora* or "thematic analysis" or "discourse analysis" or "grounded theory" or "interpretive phenomenological analysis" or "conversation analysis" or "content analysis" or ethnograph* or "Q method*").mp. [mp=title, abstract, full text, caption text]
4	1 and 2 and 3
5	Limit 4 to original articles
6	5 NOT child*.mp. [mp=title, abstract, full text, caption text]

Applied Social Sciences Index and Abstracts

Search terms	
1	(sexuality or sex behavio?r) and (qualitative or explora*) and (patient* or resident*)

ProQuest Dissertations & Theses

Search terms	
1	(sexuality or sex behavio?r) and (qualitative or explora*) and (patient* or resident*)

Appendix B

Data extraction tool

Authors and Year:

Study details	Location	
	Research question	
	Theoretical framework	
Participants	Population	
	Age (range, mean)	
	Gender (%)	
	Ethnicity (%)	
	Recruitment / sampling method	
Data collection	Method (interviews, focus groups, documents, etc.)	
	Who collected the data?	
	Were data translated or interpreted?	
	How were data prepared for analysis? (E.g. transcribed, documents grouped into categories, etc.)	
Analysis	Method (thematic analysis, IPA, Grounded theory, etc.)	
Epistemology	If reported, what was the study's epistemological stance?	
Validity	What validation methods were used? (E.g. member validation, audit trail, etc.)	
Reflexivity	Did the study report engaging in reflexivity?	
Findings	How are the results presented?	
Category 1	Title:	

(include title, description as given, verbatim extracts of data and / or authors' analytic commentary of the data).		
Category 2	Title:	
Category 3	Title:	
Category 4	Title:	
Category 5	Title:	
Category 6	Title:	
Category 7	Title:	
Category 8	Title:	
Authors conclusions	Conclusion (author's concluding remarks, key findings).	
	Limitations identified by authors	
	Implications identified by authors	
	Key references (not identified by search strategy).	
Comments	Anything else of note about this study.	

Tables

Table 1: Full-text articles cited during the systematic literature review but not included for synthesis, and reasons for exclusion.
Table 2: Characteristics of studies selected for inclusion.
Table 3: Summary of the quality appraisal process.
Table 4: Themes identified from the synthesis of studies.

Table 1. Full-text articles cited during the systematic literature review but not included for synthesis, and reasons for exclusion.

Reference	Reason for exclusion
Bauer, M. (1999). Their only privacy is between their sheets. *Journal of Gerontological Nursing, 25 (8),* 37-41.	Not a first-person perspective.
Bowden, G. & Bliss, J. (2009). Does a hospital bed impact on sexuality expression in palliative care? *British Journal of Community Nursing, 14 (3),* 122-126.	Not primary research.
Chamberland, L. (2003). Elderly women, invisible lesbians. *Canadian Journal of Community Mental Health, 22 (3),*	Full-text unavailable in English.
Davidson, J. (2008). Out of sight, out of mind: An exploration of the sexuality experiences of women with enduring mental illness. *Whitireia Nursing Journal, 15,* 59.	Full-text unavailable.
Everett, E. (2007). Ethically managing sexual activity in long-term care. *Sexuality and Disability, 25,* 21-27.	Not primary research.
Fitzgerald, C. & Withers, P. (2013). 'I don't know what a proper woman means': what women with intellectual disabilities think about sex, sexuality and themselves. *British Journal of Learning Disabilities, 41 (1),* 5-12.	Participants not in residential healthcare.
Hordern, A. J. & Street, A. (2007). Let's talk about sex: risky business for cancer and palliative care clinicians. *Contemporary Nurse,* 27 *(1),* 49-60.	Not a first-person perspective.
McCann, E. (2010).Investigating mental health service user views regarding sexual and relationship issues. *Journal of Psychiatric and Mental Health Nursing, 17,* 251–259.	Participants not in residential healthcare.
Perz, J. & Ussher, J. M. (2013). Constructions of sex and intimacy after cancer: Q methodology study of people with cancer, their partners, and health professionals. *BMC Cancer, 13 (1),*1-13.	Participants not in residential healthcare.
Redelman, M. J. (2008). Is there a place for sexuality in the holistic care of patients in the palliative care phase of life? *American Journal of Hospice and Palliative Medicine, 25 (5),* 366-371.	Not primary research.
Southard, N. Z. & Keller, J. (2009). The importance of assessing sexuality: A patient perspective. *Clinical Journal of Oncology Nursing, 13 (2),* 213-217.	Participants not in residential healthcare.
Taylor, B. (2011) The impact of assistive equipment on intimacy and sexual expression. *The British Journal of Occupational Therapy, 74 (9),* 435-442.	Participants not in residential healthcare.
Taylor, B. (2014). Experiences of sexuality and intimacy in terminal illness: A phenomenological study. *Palliative Medicine, 28 (5),* 438-447.	Residents indistinguishable from community sample.
Vaughn, M., Silver, K., Murphy, S., Ashbaugh, R. & Hoffman, A. (2015). Women with disabilities discuss sexuality in San Fransisco focus groups. *Sexual Disabilities, 33,* 19-46.	Participants not in residential healthcare.
Wylie, K. R., Wood, A. & McManus, R. (2013). Sexuality and old age. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz, 56 (2),* 223-230.	Not primary research.

Reference	Reason for exclusion
Yacoub, E. & Hall, I. (2008). The sexual lives of men with mild learning disability: a qualitative study. *British Journal of Learning Disabilities, 37,* 5-11.	Participants not in residential healthcare.

Table 2. Characteristics of studies selected for inclusion.

Study number	Author(s), year of publication and country	Participant numbers	Care environment	Data analysis method	Research question
1	Röndahl, Innala & Carlsson, 2006, Sweden	27	General hospital	*Not specified*	What do lesbian women and gay men say about their experiences of nursing in hospital care?
2	Brown, Reavey, Kanyeredzi & Batty, 2014, UK	20	Medium secure forensic psychiatric hospital	Thematic analysis	How do patients manage their sexuality when in hospital?
3	Lemieux, Kaiser, Pereira & Meadows, 2004, Canada	10	Acute palliative care unit, hospice, palliative home care	Immersion/ crystallization	What is the meaning of sexuality to palliative patients?
4	Jenkins, Walker, Cohen & Curry, 2010, USA	1	Long-term care facility	Narrative analysis	What are the experiences of an older lesbian in an assisted living facility?
5	Stein, Beckerman & Sherman, 2010, USA	12 community participants, 4 residents	Community and long-term healthcare setting	Thematic analysis	What are the psychosocial experiences and concerns of gay elderly individuals living in residential healthcare facilities?
6	McCann, 2000, UK	11	Psychiatric hospital	Content analysis	What are the sexual and relationship needs of people being cared for in hospital and preparing for a return to community living?
7	Nay, 1992, Australia	20 residents, 18 nurses	Sample across 5 nursing homes	*Not specified*	What are the experiences of institutionalised elderly people and what meaning does nursing home life have for them?
8	Östman, 2008, Sweden	6 inpatients, 4 partners	Psychiatric hospital	Thematic analysis	How is the sexuality of patients and their partners affected by mental illness?
9	Frankowski & Clark, 2009, USA	*Not specified*	Assisted living facilities	*Not specified*	How is sexuality and intimacy experienced within the social models of care provided in assisted living communities?

Study number	Author(s), year of publication and country	Participant numbers	Care environment	Data analysis method	Research question
10	Bauer, Fetherstonhaugh, Tarzia, Nay, Wellman & Beattie, 2013, Australia	16 residents	Nursing homes and assisted living facilities	Constant comparative method	What are the needs of residents in relation to sexuality? What are the barriers to residents expressing their sexuality in an aged care facility?
11	Quinn & Happell, 2015a, Australia	12 nurses, 10 inpatients	Secure forensic hospital	Thematic analysis	What do participants view as the benefits and barriers to patients' involvement in sexual relationships in a forensic hospital?
12	Quinn & Happell, 2015b, Australia	12 nurses, 10 inpatients	Secure forensic hospital	Thematic analysis	What are patients and nurses perceptions of privacy and dignity for sexual relationships in a forensic mental health hospital?
13	Villar, Celdrán, Fabà & Serrat, 2014, Spain	53 staff members, 47 residents	Residential aged care facilities	Content analysis	Do participants think residents in the nursing home experience any kind of difficulty/barrier when it comes to expressing their sexual needs?

Table 3. Summary of the quality appraisal process.

CASP criteria	1	2	3	4	5	6	7	8	9	10	11	12	13
Clear statement of aims?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Research design appropriate to aims?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Recruitment strategy appropriate to aims?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y/U*	U	Y/U*	N	Y	Y	Y	Y
Relationship between researcher and participants adequately considered?	N	N	Y	N	N	N	N	N	N	N	N	N	N
Ethical issues taken into consideration?	Y	Y	Y	U	Y	Y	U	Y	N	Y	Y	Y	Y
Data analysis sufficiently rigorous?	Y	Y/U*	Y/U*	Y	Y/U*	N/U*	N	N	Y/U*	Y	N	N	Y
Clear statement of findings?	Y	Y/U*	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. Y = Yes, N = No, U = Unclear. *Where the first author and a second author disagreed on whether a criterion was met, both judgments have been presented.

Table 4. Themes identified from the synthesis of studies**.**

Theme	1	2	3	4	5	6	7	8	9	10	11	12	13
The meaning of sexuality			*			*	*		*	*			
Privates are private		*	*	*	*	*		*	*	*			*
Sectionality	*	*	*		*	*		*					
Hopes and fears	*		*	*	*	*			*	*	*	*	
Physicality of being physical		*	*			*	*		*	*	*	*	*
Adapted sexuality		*	*		*		*	*	*		*		*

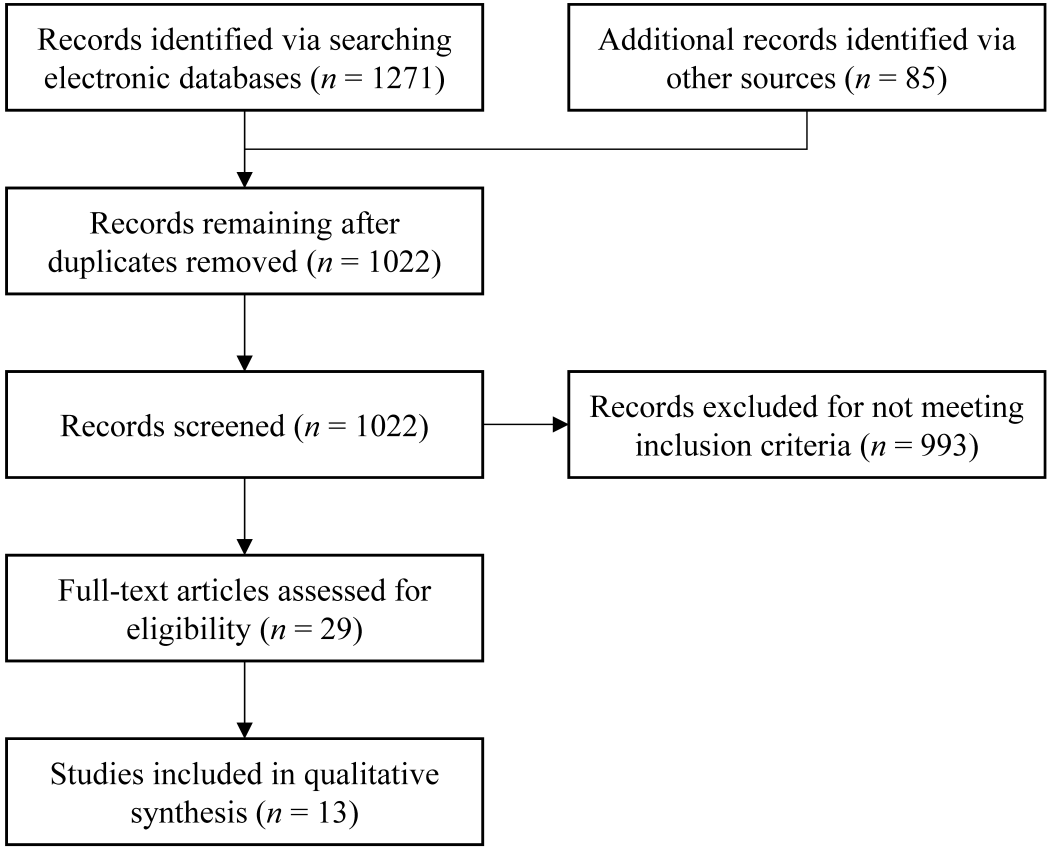
*Note: * Indicates the presence of the theme within the studies included for synthesis.*

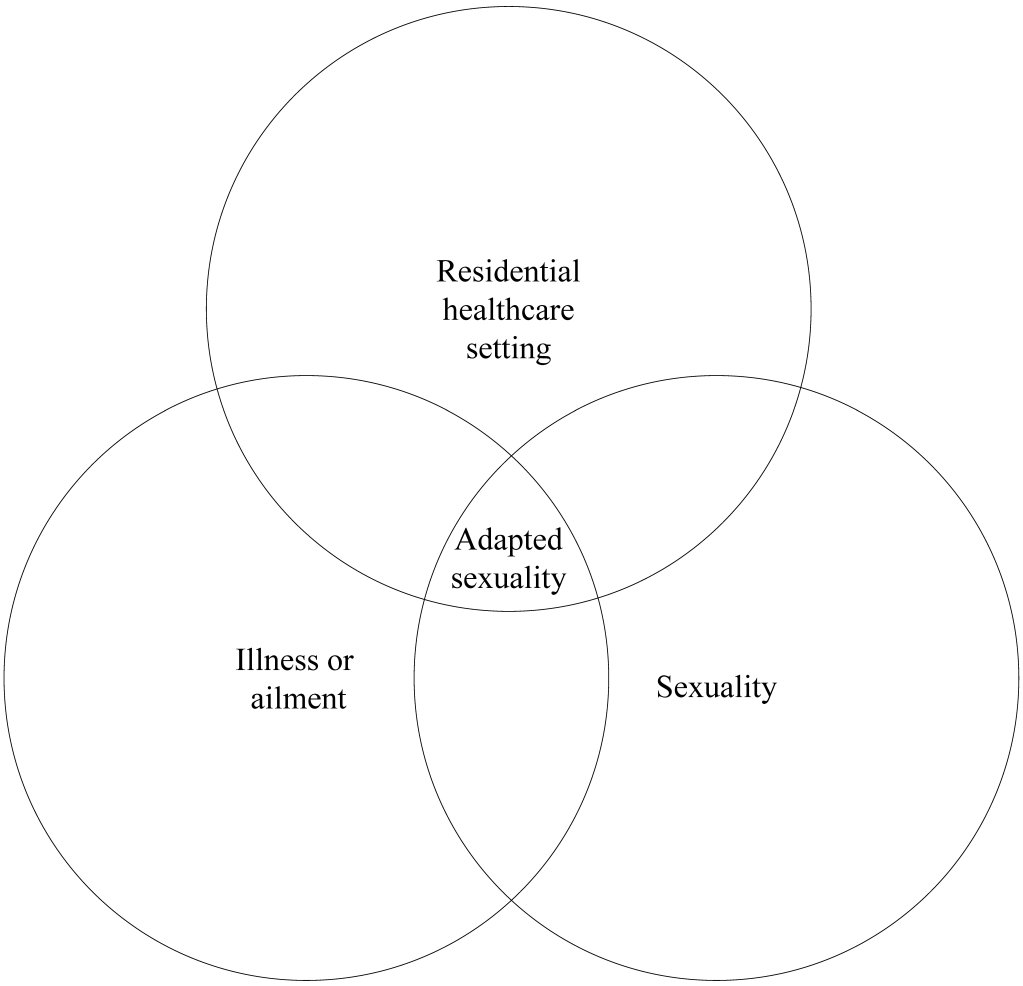
Figure captions

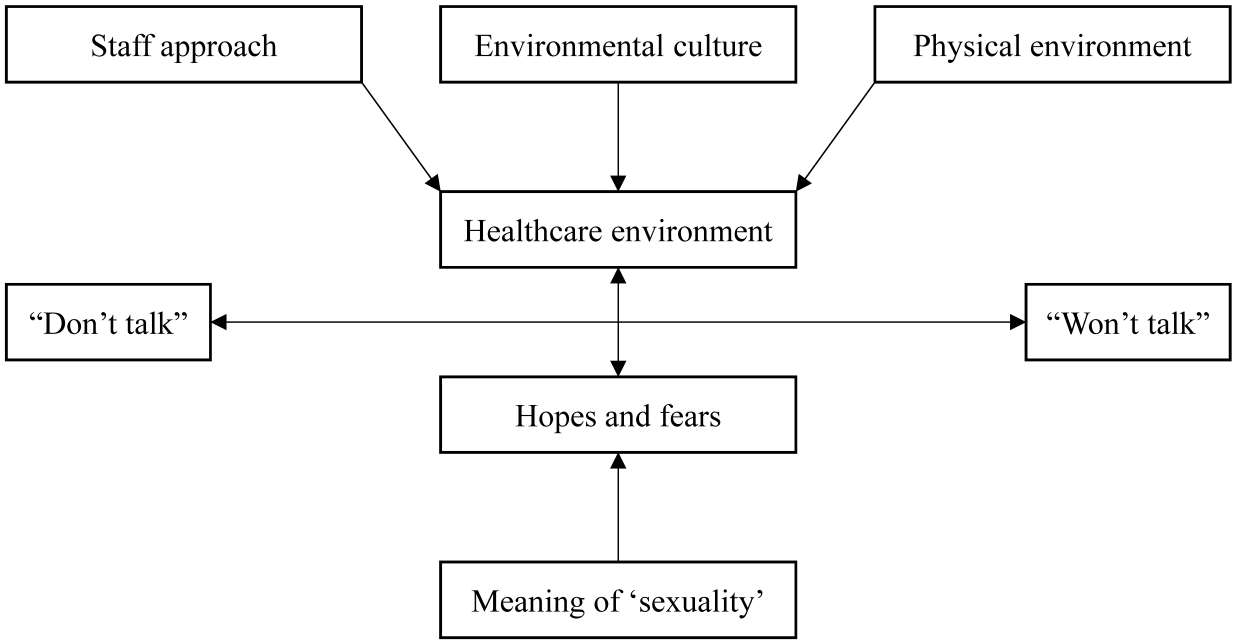
Figure 1. Process of data selection (Moher et al., 2009)

Figure 2. 'Adapted sexuality' as a consequence of how the environment, the health concern, and the individual's construct of sexuality interact and alter how sexuality is experienced by the individual.

Figure 3. The influence of an individual's construction of sexuality on their future expectations, and how the interplay between these and the residential healthcare environment impact on the communication of sexuality between patients and staff.


Records identified via searching electronic databases (n = 1271)
Additional records identified via other sources (n = 85)
Records remaining after duplicates removed (n = 1022)
Records screened (n = 1022)
Records excluded for not meeting inclusion criteria (n = 993)
Full-text articles assessed for eligibility (n = 29)
Studies included in qualitative synthesis (n = 13)


Residential
healthcare
setting
Adapted
sexuality
Illness or
ailment
Sexuality


Staff approach
Environmental culture
Physical environment
Healthcare environment
“Don’t talk”
“Won’t talk”
Hopes and fears
Meaning of ‘sexuality’