



O'Connor, S. R., Connaghan, J., Maguire, R., Kotronoulas, G., Flannagan, C., Jain, S., Brady, N. and McCaughan, E. (2019) Healthcare professional perceived barriers and facilitators to discussing sexual wellbeing with patients after diagnosis of chronic illness: a mixed-methods evidence synthesis. *Patient Education and Counseling*, 102(5), pp. 850-863.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/177151/>

Deposited on: 17 July 2019

Enlighten – Research publications by members of the University of Glasgow
<http://eprints.gla.ac.uk>

Healthcare professional perceived barriers and facilitators to discussing sexual wellbeing with patients after diagnosis of chronic illness: A mixed-methods evidence synthesis

Seán R O'Connor¹, John Connaghan J², Roma Maguire², Grigorios Kotronoulas³, Carrie Flannagan¹, Suniel Jain^{4,5}, Nuala Brady⁶, Eilís McCaughan*¹

*Corresponding author

¹ Institute of Nursing and Health Research, Ulster University, Jordanstown, UK.

² Department of Computer and Information Sciences, University of Strathclyde, Glasgow, UK.

³ School of Medicine, Dentistry and Nursing, University of Glasgow, Glasgow, UK.

⁴ Centre for Cancer Research and Cell Biology, Queen's University Belfast, Belfast, UK.

⁵ Clinical Oncology, Northern Ireland Cancer Centre, Belfast City Hospital, Belfast, UK.

⁶ Northern Health and Social Care Trust, Northern Ireland, UK.

Corresponding author at:

Eilís McCaughan

Professor in Cancer Care

Institute of Nursing and Health Research

Ulster University

Coleraine, Co Derry

N Ireland

BT52 1SA

Telephone: 028 70124091

Email: em.mccaughan@ulster.ac.uk

Abstract

Objectives: To explore healthcare professional perceived barriers and facilitators to discussing sexual health and wellbeing with patients after diagnosis of chronic illness.

Methods: Five databases were searched and included data were synthesised using a meta-ethnographic approach. Confidence in findings was assessed using the GRADE-CERQual framework. Searches, extraction and quality assessment procedures were conducted independently by at least two authors.

Results: Concepts extracted from 30 included studies were used to develop a conceptual framework based on five overarching themes. These were [1] individual and societal attitudes to sex and sexual wellbeing, [2] patient specific factors, [3] organizational and professional factors, [4] strategies to overcome barriers in practice and [5] perceived training needs. Healthcare professionals acknowledged the importance of discussing and providing support for sexual wellbeing needs, but recognized it is not routinely provided.

Conclusions: While patient specific factors and organizational issues such as lack of time were frequently identified as barriers, intra-personal and social perceptions appear to have the strongest influence on healthcare professional perspectives.

Practice implications: Brief education and tools to support healthcare professionals to have effective conversations with patients are required. These should address social barriers, normalise sexual issues, and support healthcare professionals to initiate discussions around sexual concerns.

Keywords: Communication, Sexual Wellbeing, Quality of life, Chronic illness.

1. Background

With an ageing population, the prevalence of chronic illness and multi-morbidity is increasing [1,2]. Chronic illness and associated treatment related side-effects can have a major impact on an individual's sexual function and wellbeing [3]. These changes represent a major quality of life issue which can result in high levels of anxiety, depression and relational dis-satisfaction [4,5], and patients frequently report that they do not receive adequate care and support for managing these concerns [6].

Sexual wellbeing is a complex and highly individualised construct which encapsulates a range of physical, emotional, mental and social components [3,7]. Approaches aimed at addressing these needs should not be restricted to purely biomedical approaches that focus on sexual dysfunction, as these approaches do not address sexual health and wellbeing in a biopsychosocial context. For healthcare professionals to adequately address sexual wellbeing concerns, they require knowledge and skills to effectively engage with patients, and briefly assess sexual health needs in order to provide appropriate evidence-based management [8]. However, it is acknowledged that discussing sexual health issues in routine practice is challenging, and that there are a number of barriers to these conversations taking place [9]. A recent systematic review exploring patient-provider communication in cancer care, reported that discussions around sexual concerns were often limited and were highly variable [10]. Key issues including a lack of clinical time to address psychological, social and sexual aspects of patient's illness experience have previously been identified as one reason for the low profile given to sexual concerns in clinical practice [11]. In addition, healthcare professionals report that they regard patients' sexual lives as too personal to ask about [12]. These patterns appear to be consistent across different clinical groups, as well as in primary care. Health care providers also often feel unequipped to deal with sexual issues and suggest there is a lack of resources to offer patients and their partners if they do identify a problem [13]. Despite the barriers identified, it has been reported that within a primary care setting, patients frequently identified that information related to sexual care should be routinely provided and that they would not object to clinicians initiating the discussion [14].

There is currently limited evidence exploring barriers to sexual health communication in chronic illness, particularly in non-cancer related conditions. Prior to the development of any interventions designed to improve healthcare professional communication and quality of care around sexual

concerns, a detailed understanding of these challenges and how they can be addressed is required.

1.1. Objectives

To explore healthcare professional perceived barriers and facilitators to discussing sexual health and wellbeing with patients after diagnosis of chronic illness.

2. Methods

The review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [15] and followed an *a priori* protocol developed by the review authors.

2.1. Search strategy

A systematic search strategy using guidelines recommended by the Cochrane Qualitative Research Methods group [16] was carried out by combining key Medical Subject Heading (MeSH) terms. A search of five electronic databases (MEDLINE via Ovid, EMBASE, CINAHL, AMED, PsycINFO) was conducted. To facilitate a synthesis of current evidence, databases were searched from 01st January 2000 to 30th June 2017. A final, updated search was then carried out up to the 30th October 2017. No additional limitations were applied to the searches. The search strategy was independently peer reviewed [17] and is shown in Figure 1. Grey literature [18] was identified from <http://www.opengrey.eu/> and google scholar using combinations of key terms from the primary Medline search (for example: sexual health, chronic disease, health Communication) to locate projects in progress, guidelines and policy documents. To minimise selection bias, two authors [SOC, JC] independently screened search outputs for eligible studies, compared selections, and resolved disagreement by discussion with review authors. Following removal of duplicates, potentially relevant citations were imported into EndNote.

2.2. Criteria for considering studies in the review

Studies were required to use qualitative or quantitative methods to examine perspectives of healthcare professionals on discussing sexual wellbeing with patients after diagnosis of chronic illness; or explore factors perceived to be barriers or facilitators to these discussions. For the purposes of the review, chronic illness included cancer, cardiac or respiratory disease, diabetes, long-term musculoskeletal conditions, or non-acute neurological conditions. Qualitative data from case studies, phenomenological studies, or mixed-method, grounded theory or ethnographic

studies using interviews or focus group methods and thematic analyses were included. Quantitative data from studies using survey or questionnaire based methods to explore healthcare professionals' views on discussing sexual wellbeing were also included. Studies were excluded if they involved non-clinical or mixed populations where data could not be extracted separately (e.g., primary care settings). Studies involving sexual health screening programmes or other preventative interventions were also excluded.

2.3. Quality assessment

The ten item Critical Appraisal Skills Programme (CASP) checklist was used to appraise qualitative research [19]. This includes questions covering: adequacy of methods including recruitment, data collection and analysis; influence of the researcher / participant relationship; reporting of findings and overall value [19]. The Confidence in Findings from Qualitative Evidence Syntheses (GRADE-CERQual) framework [20] was also used. This included assessment of methodological limitations, relevance, (extent to which evidence is applicable), adequacy of data (richness and quantity of supporting data), and coherence (how well findings are grounded in the primary evidence) [21]. A modified, eleven item checklist was used to evaluate the quantitative studies using survey or questionnaire methods [22]. These questions covered assessment of sampling methods and sample size, response rate and any confounding variables that might affect the study. Both checklists were used to independently assess included studies by at least two reviewers [SOC, JC, RM, GK] with each question marked as 'yes', 'no' or 'unclear'. An overall score was assigned based on the number of 'yes' responses. Quality assessment was not used to determine whether studies were included in the review. Although there is variation in quality assessment methodologies used to evaluate mixed-methods reviews [23], these methods have been widely used and endorsed [24,25].

2.4. Data extraction and meta-synthesis

Prior to extraction, all papers were reviewed to ensure a clear and coherent understanding of the included evidence. At least two authors [SOC, JC, GK, RM] used a standardised form to independently extract data from each study. This form was piloted on two unrelated papers and minor modifications made prior to extraction.

Descriptive data were extracted on author, publication year, journal, language, participant group, care setting, data collection method, analysis method, framework used. Outcomes were extracted for quantitative data. For the thematic meta-synthesis of qualitative evidence, key data extracts

from participants in the included studies (first order interpretations), and explanations of participant data by authors of the primary studies (second order interpretations) were extracted using the same standardised form. Any disagreements during extraction were resolved through consensus between review authors. Second order interpretations were then added to a separate table and similar concepts were grouped with explanations for how studies were related. These were translated using 'reciprocal translation' to connect concepts in sequence [26]. This process was then used to create the third order interpretations, and overall themes [27,28]. (See Table 1 for an example) As part of the overarching synthesis, integration of quantitative data was achieved by synthesising findings into matching themes from the qualitative meta-synthesis.

3. Results

Following removal of duplicate citations and title and abstract screening of 4376 articles, 148 papers were reviewed in full-text form. From these, 30 met the inclusion criteria and were assessed as part of the review. A PRISMA flow diagram showing the process of study selection is shown in Figure 2. Twelve papers using qualitative methods and an additional 18 used quantitative methods. Study characteristics are summarised in Table 2 and Table 3. Total number of healthcare professionals included in the qualitative methods studies was 288. Sample size ranged from 8 to 43. All but one qualitative studies used individual, face-to-face interviews to collect data and analysis methods generally involved accepted methods of coding and thematic synthesis; with a number using clearly stated frameworks or methodologies to guide analysis. These included phenomenological analysis, grounded theory, and framework analysis. Instruments used in quantitative studies included existing questionnaires (e.g., sexual attitudes and beliefs survey), or questionnaires developed by study authors. Response items ranged from 8 to 72 items. For these studies, 3049 participants were included, with sample sizes ranging from 61 to 477.

Participants were sampled from a range of professional groups, including nursing and medical staff, psychologists, physiotherapists, occupational therapists and social workers.

The majority of the studies [23/30] were focused on those working within cancer services with the remaining in cardiac, neurological or rheumatology care settings. The mean CASP rating was 5.5/10 (SD: 1.7), ranging from 2 to 9. Studies broadly included good descriptions of methods and clear statements of findings, but lacked detailed assessment of potential reporting bias. The mean checklist score was 5.8/11 (SD:1.5) with scores ranging from 3 to 8. The majority of studies did

not include sufficient detail regarding reliability and validity of the surveys or questionnaires used, and did not include attempts to estimate an appropriate sample size. Mean participant response rate was 49% ranging from 27 to 82% but response data was not reported in five studies.

Assessment of overall confidence in findings was made using the GRADE-CERQual framework (Table 4). Studies were generally found to have minor methodological limitations and were all rated as satisfactory, except for a single study which was judged to contain substantial methodological issues in reporting and analysis [29]. Most (11/12 qualitative studies [29,30-39]; 15/18 quantitative studies [40-54]) provided direct evidence related to the aims of the review, and the broad themes that were identified. Four studies [55-58] were assessed as providing partially relevant evidence, as they examined participant perspectives in the context of a training intervention or programme. Overall confidence in review findings was rated as 'moderate' since coherent, supporting data was provided by around half of the studies for each theme [20]. This suggests that overall, evidence was variable and moderately coherent.

3.1. Thematic analysis

A total of 63, individual second-order concepts were extracted from the included studies. After grouping similar or repeated concepts, 49 were identified for inclusion in the meta-synthesis. Three additional concepts were identified from quantitative studies. These 52 concepts were then reciprocally translated into five third order themes. The overall themes that emerged were: [1] individual and societal attitudes to sex and sexual wellbeing [n=13], [2] patient specific factors [n=14], [3] organizational and professional factors, [n=17], [4] strategies to overcome barriers in practice [n=4], and [5] perceived training needs [n=4] (See Table 5). Themes 1, 2 and 3 related to key barriers, while themes 4 and 5 related to participants' specific views on facilitators to overcome identified barriers.

Theme 1: Individual and societal attitudes to sex and sexual wellbeing

A central theme emerging from the meta-synthesis was related to influence of social interpretations and attitudes to sex and sexuality. Nineteen studies cited three separate attitudes to sex or sexual wellbeing as a barrier to discussing the issue with patients. These included fear of embarrassment, not being comfortable with the topic and not wishing to cause offence. Personal embarrassment was reported as a significant issue by at least half of respondents in many quantitative studies, [44-48, 51-54,56]. However, respondents in a small number of studies reported substantially lower levels of embarrassment or discomfort with the subject [40,41,43,57].

This factor appeared to be dependent on age, years of experience and area of practice. For example, Discomfort was also attributed to level of rapport or connection with whoever the conversation is being held [37]. Definition of sexuality also varied and these concepts were seen as multidimensional, and highly subjective. Participants often had greatest difficulty defining sexuality and wellbeing when they reported higher levels of personal discomfort [33]. These participants were frequently less likely to articulate personal definitions of sexuality and discuss how this might influence their practice [32].

Participants also used different terms to describe sexual issues and reported focusing on more 'objective' clinical factors which they felt more comfortable with. For example, focusing on sexual function or biomedical aspects of care. Others acknowledged the influence of their 'personal boundaries' [31,39,43,44] and how these factors might limit the ability to discuss sexual wellbeing openly, in both a personal and professional sense [36]. Further reflectivity was seen among participants who described sexuality as being focused on relationships and 'closeness' as opposed to just intercourse [32]. Those who reported having more frequent conversations about sexual concerns described comfort with their own sexuality as an important prerequisite [35].

Others typically distanced themselves as an individual from these factors and discussed them by citing examples of others, and why 'they' might avoid talking about sex with patients. Personal discomfort was also cited as a factor even when taking into account professional factors. Some healthcare professionals felt that discomfort and lack of confidence could be a barrier, even with sufficient knowledge and understanding of the issue [36,49,40,50,51]. Sex was also often referred to as 'risky' or 'taboo' subject [33,38] with meaningful discussion often limited even when healthcare professionals were normally able to talk about other 'sensitive' issues [32,44].

Healthcare professionals also discussed using different approaches to actively avoid having discussions, or to discuss sexual wellbeing only within their own personal level of comfort [33,34,39,52,54]. Some healthcare professionals reflected their own views when discussing issues that served as barriers, such as being from an older generation that didn't talk about sex [35]. Cultural and gender issues also played a significant part in participant views. Gender was cited as a strong factor influenced by different outlooks on sexual wellbeing, including sense of self, self-image and esteem [39,42]. Moreover, some suggested that they would not address sexual issues with single or widowed patients [37]. The complexity of sexual function in women was also perceived as being more 'problematic' for woman than men since it is linked to emotions, rather than being a 'functional' problem [34].

Theme 2. Patient specific factors

Twenty-six studies included 14 patient related factors seen as potential barriers to discussions. These factors related to phase of care, the specific illness and likely patient perceptions. Not wanting to cause the patient embarrassment was cited as being an equally important potential barrier as the issues of personal embarrassment outlined in the previous section. From survey data, this issue was seen as a barrier in around 45-50% of respondents [44,47,51,55]. A small number acknowledged that the patient discomfort they thought might be a barrier could actually reflect their own embarrassment [35]. Healthcare professionals frequently reported patient related factors and situations where it is not appropriate to discuss sexual concerns, particularly in specific patient groups or settings. Concerns were raised that if sexuality was discussed, it could cause a negative reaction. For example, in situations where the patient had an 'unrelated' (or non-reproductive) cancer diagnosis.

Other barriers included issues around patients being too unwell, or in a very acute stage of care, such as immediately post-surgery [32]. Further observations were linked to a perception that patients would support this view since they would be primarily concerned with their prognosis over and above more 'personal issues' [34,37]. These views were not only limited to the more acute phases of care but were also discussed by other participants as a 'quality of life' issue which is also more important in the longer term (after the treatment phase); and which, if raised during treatment, might cause a patient to question the healthcare professional's priorities [42,51]. These perceptions were however, not universal and others stated strongly that it is critical to ensure all patients have the opportunity to discuss concerns at various time-points in their treatment.

'I suppose when it comes to raising sexuality issues what we normally say is our number one rule is to assume nothing, so we ask everybody no matter what their age, their cultural background, their relationship status because from time to time we have had people raise questions that we might not otherwise have predicted' (Psychologist) [33].

A number of participants raised the issue of advice on sexual activity given in the early phases of treatment, and the likely impact of treatment. Others discussed the importance of dispelling common preconceptions around sexuality and sexual activity. This was frequently cited as a factor in providing reassurance and appropriate information to patients, as well as a means of initiating discussions, or ensuring that patients feel able to bring up concerns [40,44]. Addressing concerns

was also seen as critical, even if only raised briefly to facilitate patient awareness, normalise issues, and make it easier to return to the topic at a later time-point [36].

Theme 3: Organizational and professional factors

A substantial number of barriers (n=17) related to organizational or professional issues were identified from 27 studies. These issues were closely related to the setting in which participants practiced. Barriers identified were lack of time to address sexual issues, lack of professional knowledge and uncertainty over professional role. Within a health system context, many barriers were seen to be related to a focus on biomedical models of care, where sexuality is generally considered from a 'functional' perspective. One observation reported in a study, exploring constructs of sexuality after cancer [55] was related to medico-legal issues with a participant indicating that they avoided discussions as they feared being sued for crossing 'boundaries'. This barrier was not cited elsewhere in the evidence.

Healthcare professionals frequently discussed lack of privacy as an important barrier [31,34,37,39,40,42,44-46]. Lack of time was a barrier across professional groups in a number of studies [32,33,37,40,41]; and some suggested not discussing sexual concerns was often reasonable due to its complexity. Conversely, others were clear that issues should be discussed, particularly when treatment can impact sexual wellbeing. In this context, discussing concerns, particularly in the context of treatment induced side-effects was seen as being an important responsibility.

'Sometimes, a patient raises the topic, but if not, it is absolutely our task to address sexuality. You irradiate somebody for seven, eight weeks, so you interact intensively. Yes, I do think that is part of our treatment and care provision. We cause it' (Radiologist) [38].

This contention was seen by others to be complicated by the presence of a partner, family member or friend which limited opportunity for discussion. However, this was also seen as not being a reasonable barrier since practice could be adapted to cope with the issue. Some suggested that certain groups were better placed to address concerns [32,34], but this viewpoint was not common. Others indicated that they felt able to manage these concerns, especially where they had ongoing contact with patients [34,40]. It was also acknowledged that assuming other professionals will talk about sexuality can result in it not being discussed by anyone [40]. Lack of training was a major issue that participants said limited their ability to deal with sexual concerns,

especially patient's questions around 'when will things go back to normal?' [38]. Healthcare professionals also cited reactions of colleagues as a constraining influence, and identified a concern that they would be seen as 'unprofessional' if they frequently attempted to address patient's sexual concerns [35]. Participants also indicated that sexual concerns were frequently not discussed due to a lack of routinely used clinical documentation [34]. In a similar manner, lack of onward referral option was also considered to be a reason to not engage with patients [32].

Theme 4: Strategies to overcome barriers in practice

Four concepts derived from 11 separate studies were identified. Five studies included specific mentions of active strategies to enable discussions on sexual wellbeing (as part of an intervention or programme), and other approaches were indirectly extracted from the evidence as they were discussed as responses to identified barriers. Key strategies were related to use of tools or systems to integrate sexual wellbeing into holistic care. Other approaches included use of brief information to normalise sexual wellbeing discussions, and better multidisciplinary support, including referral options [34,37]. Where sexual health concerns were included as an integral part of assessment, participants thought that this could normalise discussions and ensure that assessment occurred during follow-up appointments if not raised initially. Other participants suggested that making it standard practice, could help to remove 'decision making'. A similar approach was highlighted that served to ensure patients were informed what the assessment would cover, including sexuality, even when it might not happen immediately.

'...even if you only briefly raise the topic, then patients have heard about it. This makes it easier to come back to the topic, and makes it clear that he or she can bring up the matter'. (Nurse) [38].

The importance of appropriate communication approaches was also discussed frequently. This included use of active listening [36] and open ended questions [30]. Normalising sexual wellbeing discussions was seen as important [34,36,40,46,48]. This was talked about in broader terms than the clinical setting in which participants practiced. Mass media was also considered to have a role in normalizing conversation about sex and sexual dysfunction. Advertisements concerning erectile dysfunction and prostate problems were cited as an example of this [39]. A further 'strategy' that was mentioned was the use of humour to make light of a 'bad situation'. Although this was often mentioned, participants acknowledged this may be directed at making themselves or colleagues feel comfortable, without thinking how this might be interpreted by the patient [32].

Theme 5. Perceived training needs

Lack of training in discussing sexual concerns was cited as a major barrier. The number of studies that directly addressed views on exactly what training needs are required was limited, but there was evidence from studies that explored views on training interventions. The four main concepts that emerged were derived from 14 studies. This included use of, and training in models of sexual health assessment and support, communication training and peer mentoring. Inadequate formal support in the case where there is no obvious referral pathway was also seen as an issue. This was addressed by participants who discussed the usefulness of observing colleagues engaged in sexual care discussions [36]. Routine provision of information to ensure awareness of available resources was also seen as important [40,41]. This was seen as vital to ensuring there is a sense that addressing sexual issues and concerns is part of clinician's role. Some participants with a more formalised role in sexual care support, including specialist nurses, counsellors and clinical psychologists, and who therefore reported that they more frequently engaged with patients; did identify being comfortable with sexual discussions. Some of these participants did highlight that this comfort was linked to the time and practice needed to develop their confidence in the area. There was acknowledgement of the need for psychosocial education and interventions [32,35,38]. Basic training as part of communication training and ongoing professional development was highlighted as an appropriate and implementable approach that could improve confidence, and increase likelihood of communication happening in a clinical context [32,35]. However, there was limited discussion or exploration around whose role it might be to co-ordinate and deliver training.

3.2. Development of a conceptual framework

The third-order themes developed based on the findings of this meta-synthesis were closely inter-related. Examining how these themes relate conceptually, demonstrates how healthcare professional views are influenced by personal and social perspectives on sexual wellbeing, condition specific patient issues, and key structural factors (See Table 5).

4. Discussion

This is the first review using a mixed-methods evidence synthesis to explore views on discussing sexual wellbeing with patients after diagnosis of chronic illness. Findings were used to identify five core themes covering important barriers and facilitators. These themes were closely related and there was a high level of coherence across the evidence, with many barriers cited frequently by healthcare professionals working across different areas of practice. Conceptual analysis of the themes suggested that views and practices are highly influenced by attitudes and perceptions of

sexuality, and that many barriers identified in previous research examining communication in cancer care settings are also found in other areas of practice.

Sex and sexual concerns were seen as being sensitive issues which were difficult to discuss with patients [32,35]. Healthcare professionals often reported lacking confidence and skills to proactively engage with patients, but recognized this can lead to unmet needs and sub-optimal patient management [36,40]. Addressing sexual concerns was generally seen as an important and valuable part of routine care [36,38,41,44,46], but issues were raised around responsibility for addressing issues; and around patient factors that might act as barriers to discussions. There was a frequent emphasis on biomedical models of care that suggested sexual issues were typically physiological and manageable through pharmacological support or other medical intervention [29,33,35,40]. When healthcare professionals spoke about psychological aspects of care they were less clear how concerns should be managed [32,34].

Some barriers to discussing sexual wellbeing related to factors such as age and ethnic background, but one factor cited more frequently in the evidence was phase of care [30]. This finding is supported by evidence from observational studies exploring how healthcare professionals have discussions around sexual wellbeing in practice [59-61]. This issue was cited as a reason for sexual concerns being a low priority, during early or acute phases of care, and in rehabilitation settings or in primary care [37,39].

Participants frequently raised the issue of wishing to avoid embarrassing or offending patients [30,32,34,39]; or preferring to wait until patients raised sexual issues [38,40,44,46]. However, this contention is refuted by evidence from studies exploring patient perspectives. This evidence indicates that patients are typically comfortable with, and expect healthcare professionals to discuss sexual concerns [14,62-64]. Furthermore, other studies indicate that patients frequently report being dissatisfied with the level of information and support provided to them on the impact of treatment on sexual function [65,67]. Provision of adequate information and support is particularly essential in clinical populations where sexual issues can occur as an indirect, or direct effect of treatment. For example, in a recent population-wide patient-reported outcome study of 30,000 men, poor sexual function was common (81%), regardless of stage of care and that over half of men (56%) received limited or no support [68].

A topic emerging from this analysis, was that professional and organizational barriers to discussing sexuality with patients (for example, lack of time, privacy and lack of referral options) may actually reflect personal discomfort [69]. Approaching sexual concerns in this manner may also justify the avoidance of the issue and reinforce gaps in care. Other evidence indicates that patients often report being unprepared for changes in sexual wellbeing associated with chronic illness or side-effects of treatment [10]. As a result, many are left to cope with these negative changes without adequate support. This can have a substantial long-term influence on overall quality of life [4,5]. Since many patients may not be aware of how treatment affects sexual function and wellbeing, healthcare professionals need to ensure they inform patients about potential side-effects, whether or not patients raise the topic.

4.1. Strength and limitations

A robust review protocol and systematic approach was used in the review. Use of a meta-synthesis incorporating a relatively large body of qualitative and quantitative evidence, as well as a conceptual framework to interpret findings, adds to its overall strength. However, meta-synthesis is an approach to integration of research evidence for which there are no agreed standardized methods [70-72]. One limitation is that the review could not fully explore differences between professional groups. Professional roles and identities may have influenced participant responses. Finally, it is important to recognize that data is primarily from studies including those working in cancer or cardiac care settings.

4.2. Conclusions

A number of inter-related factors can substantially influence healthcare professional perspectives on discussing sexual wellbeing with patients living with chronic illness. Healthcare professionals identified a number of barriers limiting how often, or if, these discussions take place. These included lack of knowledge and training, as well as structural constraints found in the clinical setting. While these findings may suggest structural or organizational changes are required to normalise sexual concerns; many barriers were more closely related to personal and social perspectives, including discomfort and fear of embarrassment.

4.3. Implications for practice

Overcoming these barriers is vital to ensure that sexual issues are acknowledged and recognized as impacting on patient quality of life, regardless of the condition present, age or gender. To overcome barriers, a number of changes may be required at the individual and system level. For

example, effective integration of tools designed to facilitate open communication around sexual concerns into routinely used clinical documentation could be used to normalise and acknowledge common sexual concerns. Brief education and support to improve communication and engagement skills as well as peer support and mentoring could be used [73-76].

Conflicts of interest

None.

Source of funding

This work is funded by the Movember Foundation, in partnership with Prostate Cancer UK, as part of the TrueNTH programme.

Authors' contributions

SOC designed and carried out the database searches and together with JC determined studies for inclusion in the review. SOC, JC, RM, GK and EMcC performed all data extraction, quality assessment and thematic analysis procedures. SOC and EMcC drafted the first version of this manuscript and all authors contributed to manuscript revisions and approved the final version.

Acknowledgements

The authors wish to acknowledge the valuable feedback provided on the manuscript by Professor Kader Parahoo and Professor Suzanne McDonough (Ulster University).

References

1. MY Wei , MU Kabeto, AT Galectin, KM Langa. Physical Functioning Decline and Mortality in Older Adults with Multimorbidity: Joint Modeling of Longitudinal and Survival Data. *J Gerontol A Biol Sci Med Sci.* 26. (2018). [Epub ahead of print]
2. SM Ornstein, PJ Nietert, RG Jenkins, CB Litvin. The prevalence of chronic diseases and multimorbidity in primary care practice: a PPRNet report. *J Am Board Fam Med.* 26 (2013) 518-24.
3. JE Verschuren, P Enzlin, PU Dijkstra, JH Geertzen, R Dekker. Chronic disease and sexuality: a generic conceptual framework. *J Sex Res.* 47 (2010) 153-70.
4. TJ Flynn, AJ Gow. Examining associations between sexual behaviours and quality of life in older adults. *Age Ageing.* 44 (2015) 823-8.
5. V Wang, CA Depp, J Ceglowski, WK Thompson, D Rock, DV Jeste. Sexual health and function in later life: a population-based study of 606 older adults with a partner. *Am J Geriatr Psychiatry.* 23 (2015) 227-33.
6. ST Lindau, LP Schumm, EO Laumann, W Levinson, CA O'Muircheartaigh, LJ Waite. A study of sexuality and health among older adults in the United States. *N Engl J Med.* 23 (2007) 762-74.
7. KE Flynn, L Lin, KP Weinfurt. Sexual function and satisfaction among heterosexual and sexual minority U.S. adults: A cross-sectional survey. *PLoS One.* 12 (2017) e0174981.
8. M Bauer, E Haesler, D Fetherstonhaugh. Let's talk about sex: older people's views on the recognition of sexuality and sexual health in the health-care setting. *Health Expect.* 19 (2016) 1237-1250.
9. K Dyer, R das Nair. Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom. *J Sex Med.* 10 (2013) 2658-70.

10. JB Reese, K Sorice, MC Beach, LS Porter, JA Tulskey, MB Daly, SJ Lepore⁸. Patient-provider communication about sexual concerns in cancer: a systematic review. *J Cancer Surviv.* 11 (2017) 175-188.
11. G Kotronoulas, C Papadopoulou, E Patiraki. Nurses' knowledge, attitudes, and practices regarding provision of sexual health care in patients with cancer: critical review of the evidence. *Support Care Cancer.* 17 (2009) 479-501.
12. A Richards, R Dean, GH Burgess, H Caird. Sexuality after stroke: an exploration of current professional approaches, barriers to providing support and future directions. *Disabil Rehabil.* 38 (2016) 1471-82.
13. A Gleeson, E Hazell. Sexual well-being in cancer and palliative care: an assessment of healthcare professionals' current practice and training needs. *BMJ Support Palliat Care.* 7 (2017) 251-254.
14. RD Clark, AA Williams. Patient preferences in discussing sexual dysfunctions in primary care. *Fam Med.* 46(2 (2014) 124-8.
15. D. Moher, A. Liberati, J. Tetzlaff, D.G. Altman, Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement, *PLoS Med.* 6 (2009) e1000097.
16. J Noyes, A Booth, M Cargo, K Flemming, R Garside, K Hannes, A Harden, J Harris, S Lewin, T Pantoja, J Thomas. Cochrane Qualitative and Implementation Methods Group Guidance Series - Paper 1: Introduction. *J Clin Epidemiol.* 17 (2017) 31353-7.
17. J McGowan, M Sampson, DM Salzwedel, E Cogo, V Foerster, C Lefebvre. PRESS peer review of electronic search strategies: 2015 guideline statement. *J Clin Epidemiol.* 75 (2016) 40-6.
18. M Boeker, W Vach, E Motschall. Google Scholar as replacement for systematic literature searches: good relative recall and precision are not enough. *BMC Med Res Methodol.* 13 (2013) 131.

19. Critical Appraisal Skills Programme (2018). CASP Qualitative Checklist. [online] Available at: <https://casp-uk.net/casp-tools-checklists/>. Accessed: 10/01/2018.
20. S Lewin, C Glenton, H Munthe-Kaas, B Carlsen, CJ Colvin, M Gülmezoglu J Noyes, A Booth, R Garside, A Rashidian. Using Qualitative Evidence in Decision Making for Health and Social Interventions: An Approach to Assess Confidence in Findings from Qualitative Evidence Syntheses (GRADE-CERQual). *PLoS Med.* 12 (2015) e1001895
21. S Lewin, A Booth, C Glenton, H Munthe-Kaas, A Rashidian, M Wainwright, MA Bohren, Ö Tunçalp, CJ Colvin, R Garside, B Carlsen, EV Langlois, J Noyes. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. *Implement Sci.* 25 (2018) 2.
22. I Crombie. The Pocket Guide to Critical Appraisal; the critical appraisal approach used by the Oxford Centre for Evidence Medicine, checklists of the Dutch Cochrane Centre, BMJ editor's checklists and the checklists of the EPPI Centre. (2018). [online] Available at: <https://www.cebma.org/wp-content/uploads/Critical-Appraisal-Questions-for-a-Survey.pdf>. Accessed: 15/09/2017.
23. E Barnett-Page, J Thomas. Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodol.* 11 (2009) 59.
24. J Noyes. Never mind the qualitative feel the depth! The evolving role of qualitative research in Cochrane intervention reviews. *J Res Nurs.* 15 (2010) 525.
25. K Hannes, A Booth, J Harris, J Noyes. Celebrating methodological challenges and changes: reflecting on the emergence and importance of the role of qualitative evidence in Cochrane reviews. *Syst Rev.* 2 (2013)84.
26. LH Doyle. Synthesis through meta-ethnography: paradoxes, enhancements, and possibilities. *Qualitative Research.* 3 (2003) 321-344
27. R Campbell, P Pound, M Morgan, G Daker-White, N Britten, Pill R, Yardley L, Pope C, Donovan J. Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technol Assess.* 15 (2011) 43.

28. EF France, N Ring, J Noyes, M Maxwell, R Jepson, E Duncan, Turley R, Jones D, Uny I. Developing meta-ethnography reporting guidelines and standards for research (eMERGE). Protocol version 2. 2015. Available from: <http://www.nets.nihr.ac.uk/projects/hsdr/1311460> Accessed on 07/02/18.
29. ML Stead, JM Brown, L Fallowfield, P Selby. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *Br J Cancer*. 10 (2003) 666-71.
30. M D'Eath, M Byrne, S Doherty, H McGee, AW Murphy. The Cardiac Health and Assessment of Relationship Management and Sexuality study: a qualitative inquiry of patient, general practitioner, and cardiac rehabilitation staff views on sexual assessment and counseling for cardiac patients. *J Cardiovasc Nurs*. 28 (2013) E1-13.
31. SM Ferreira, O Gozzo Tde, MS Panobianco, MA dos Santos, AM de Almeida. Barriers for the inclusion of sexuality in nursing care for women with gynecological and breastcancer: perspective of professionals. *Rev Lat Am Enfermagem*. 23 (2015) 82-9.
32. M Lavin, A Hyde. Sexuality as an aspect of nursing care for women receiving chemotherapy for breast cancer in an Irish context. *Eur J Oncol Nurs*. 10 (2006) 10-8.
33. ST Lindau, H Surawska, J Paice, SR Baron. Communication about sexuality and intimacy in couples affected by lung cancer and their clinical-care providers. *Psychooncology*. 20 (2011) 179-85.
34. RM Mellor, SM Greenfield, G Dowswell, JP Sheppard, T Quinn, RJ McManus. Health care professionals' views on discussing sexual wellbeing with patients who have had a stroke: a qualitative study. *PLoS One*. 29 (2013) e78802.
35. C Olsson, AL Berglund, M Larsson, E Athlin. Patient's sexuality - a neglected area of cancer nursing? *Eur J Oncol Nurs*. 16 (2012) 426-31.

36. MJ Traa, J De Vries, JA Roukema, HJ Rutten, BL Den Oudsten.
The sexual health care needs after colorectal cancer: the view of patients, partners,
and healthcare professionals. *Support Care Cancer*. 22 (2014) 763-72.
37. JM Ussher, J Perz, E Gilbert, WK Wong, C Mason, K Hobbs, L Kirsten.
Talking about sex after cancer: a
discourse analytic study of health care professional accounts of sexual communication
with patients. *Psychol Health*. 28 (2013) 1370-90.
38. WM Vermeer, RM Bakker, AM Stiggelbout, CL Creutzberg, GC Kenter, MM ter Kuile.
Psychosexual support for gynecological cancer survivors: professionals'
current practices and need for assistance. *Support Care Cancer*. 23 (2015) 831-9.
39. EM Vieira, NJ Ford, MA Santos, LC Junqueira, A Giami. Representations
of nurses regarding sexuality of women treated for breast cancer in Brazil.
Cad Saude Publica. 29 (2013) :2049-56.
40. L Butler, V Banfield. Oncology nurses' views on the provision of sexual health in cancer
care. *J Sex Reprod Med* 1 (2001) 35-39.
41. M Byrne, S Doherty, HM McGee, AW Murphy. General
practitioner views about discussing sexual issues with patients with coronary heart disease: a
national survey in Ireland. *BMC Fam Pract*. 25 (2010) 40.
42. S Doherty, M Byrne, AW Murphy, HM McGee. Cardiac
rehabilitation staff views about discussing sexual issues with coronary heart disease patients: a
national survey in Ireland. *Eur J Cardiovasc Nurs*. 10 (2011) 101-7.
43. K Hautamäki, M Miettinen, PL Kellokumpu-Lehtinen, P Aalto, J Lehto.
Opening communication with cancer patients about **sexuality**-related issues.
Cancer Nurs.30 (2007) 399-404.

44. Y Helland, A Garratt, I Kjekken, TK Kvien, H Dagfinrud. Current practice and barriers to the management of sexual issues in rheumatology: results of a survey of health professionals. *Scand J Rheumatol.* 42 (2013) 20-6.
45. T Hoekstra, I Lesman-Leegte, MF Couperus, R Sanderma, T Jaarsma. What keeps nurses from the sexual counseling of patients with heart failure? *Heart Lung.* 41 (2012) 492-9.
46. LL Huang, J Pu, LH Liu, XB Du, J Wang, JY Li, WX Yao, XQ Zhu, R Zhang, Y Zhao, M He. Cancer department nurses' attitudes and practices in response to the sexual issues of pelvic-radiation patients: a survey in Sichuan, China. *Contemp Nurse.* 43 (2013) 146-51.
47. JO Julien, B Thom, NE Kline. Identification of barriers to sexual health assessment in oncology nursing practice. *Oncol Nurs Forum.* 37 (2010) E186-90.
48. EM Krouwel, MP Nicolai, AQ van Steijn-van Tol, H Putter, S Osanto, RC Pelger, HW Elzevier. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. *Eur J Oncol Nurs.* 19 (2015) 707-15.
49. EM Krouwel, JH Hagen, MP Nicolai, AL Vahrmeijer, H Putter, RC Pelger, HW Elzevier. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. *Eur J Surg Oncol.* 41 (2015) 1179-87.
50. EM Krouwel, MP Nicolai, GJ van der Wielen, H Putter, AD Krol, RC Pelger, L Incrocci, HW Elzevier. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? *J Sex Med.* 2015 Sep;12(9):1927-39.
51. K Leonardi-Warren, I Neff, M Mancuso, B Wenger, M Galbraith, R Fink. Sexual Health: Exploring Patient Needs and Healthcare Provider Comfort and Knowledge. *Clin J Oncol Nurs.* 1 (2016) E162-E167.
52. A Moore, A Higgins, D Sharek. Barriers and facilitators for oncology nurses discussing sexual issues with men diagnosed with testicular cancer. *Eur J Oncol Nurs.* 17 (2013) 416-22.

53. U Oskay, G Can, S Basgol.

Discussing sexuality with cancer patients: oncology nurses attitudes and views. *Asian Pac J Cancer Prev.* 15 (2014) 7321-6.

54. YC Zeng, Q Li, N Wang, SS Ching, AY Loke

Chinese nurses' attitudes and beliefs toward sexuality care in cancer patients. *Cancer Nurs.* 34 (2011) E14-20.

55. AJ Hordern, AF Street. Constructions of sexuality and intimacy after cancer: patient and health professional perspectives. *Soc Sci Med.* 64 (2007) 1704-18.

56. A Hordern, M Grainger, S Hegarty, M Jefford, V White, G Sutherland. Discussing sexuality in the clinical setting: The impact of a brief training program for oncology health professionals to enhance communication about sexuality. *Asia-Pacific Journal of Clinical Oncology.* 5 (2009) 270-277

57. JI Jonsdottir, S Zoëga, T Saevarsdottir, A Sverrisdottir, T Thorsdottir, GV Einarsson, S Gunnarsdottir, N Fridriksdottir. Changes in attitudes, practices and barriers among oncology health care professionals regarding sexual health care: Outcomes from a 2-year educational intervention at a University Hospital. *Eur J Oncol Nurs.* 21 (2016) 24-30.

58. LY Wang, A Pierdomenico, A Lefkowitz, R Brandt.

Female Sexual Health Training for Oncology Providers: New Applications. *Sex Med.* 3 (2015) 189-97.

59. L Forbat L, I White, S Marshall-Lucette, D Kelly.

Discussing the sexual consequences of treatment in radiotherapy and urology consultations with couples affected by prostate cancer. *BJU Int.* 109 (2012) 98-103.

60. NJ Sporn, KB Smith, WF Pirl, IT Lennes, KA Hyland, ER Park. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? *Psychooncology.* 24 (2015) 1167-73.

61. AK Hughes, TD Lewinson. Facilitating communication about sexual health between aging women and their health care providers. *Qual Health Res.* 25 (2015) 540-50.
62. KE Flynn, JB Reese, DD Jeffery DD, P Abernethy AP, L Lin, RA Shelby, LS Porter, CB Dombeck, KP Weinfurt. Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology* 21 (2012) 594-601
63. MR Canzona, D Garcia, CL Fisher, M Raleigh, V Kalish, CJ Ledford. Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. *Patient Educ Couns.* 99 (2016) 1814-1820.
64. M Medina, C Walker, EE Steinke, DW Wright, V Mosack , MH Farhoud. Sexual concerns and sexual counseling in heart failure. *Prog Cardiovasc Nurs.* 24 (2009) 141-8.
65. ES Zhou, SL Bober, L Nekhlyudov, JC Hu, PW Kantoff, CJ Recklitis. Physical and emotional health information needs and preferences of long-term prostate cancer survivors. *Patient Educ Couns.* 99 (2016) 2049-2054.
66. AG Driel, MJ de Hosson, C Gamel. Sexuality of patients with chronic heart failure and their spouses and the need for information regarding sexuality. *Eur J Cardiovasc Nurs.* 13 (2014) 227-34.
67. M Byrne, S Doherty, AW Murphy, HM McGee, T Jaarsma. The CHARMS Study: cardiac patients' experiences of sexual problems following cardiac rehabilitation. *Eur J Cardiovasc Nurs.* 12 (2013) 558-66.
68. A Downing, P Wright, L Hounsome, L, P Selby, S Wilding, E Watson, R Wagland, P Kind, DW Donnelly, H Butcher, JWF Catto, W Cross, M Mason, L Sharp, D Weller, G Velikova, E McCaughan, R Mottram, M Allen, T Kearney, O McSorley, DW Huws, DH Brewster, E McNair, A Gavin, AW Glaser. Quality of life in men living with advanced and localised prostate cancer: A United Kingdom population-wide patient-reported outcome study of 30,000 men. *Lancet Oncology.* (Accepted: 2018) (In Press).

69. Street RL. How clinician-patient communication contributes to health improvement: modeling pathways from talk to outcome. *Patient Educ Couns.* 92 (2013) 286-91.
70. J Noyes, A Booth, K Hannes. Cochrane Collaboration Qualitative Methods Group. Supplementary guidance for inclusion of qualitative research in Cochrane systematic reviews of interventions. Version 1 (updated August 2011) 2011.
71. R Campbell, P Pound, Morgan M, Daker-White G, Britten N, Pill R, Yardley L, Pope C, Donovan J. Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technol Assess.* 15 (2011) 1-164.
72. E Barnett-Page, J Thomas. Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodol.* 9 (2009) 59.
73. P Singy, C Bourquin, B Sulstarova, F Stiefel. The impact of communication skills training in oncology: a linguistic analysis. *J Cancer Educ.* 3 (2012) 404-8.
74. I Strada, E Vegni, G Lamiani. Talking with patients about sex: results of an inter-professional simulation-based training for clinicians. *Intern Emerg Med.* 11 (2016) 859-66.
75. G Harrison, S Hayden, V Cook. A Cushing. Improving health care professionals' feedback on communication skills: development of an on-line resource. *Patient Educ Couns.* 88 (2012) 414-9.
76. PM Moore, S Rivera Mercado, M Grez Artigues, TA Lawrie. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev.* 28 (2013)

Figure 1. Medline search terms

Database: Ovid MEDLINE(R) <1946 to October. Week 4 2017>

Search terms: (Number of Returns)

SEARCH CATEGORY 1: Health Professionals

- 1 exp Health Personnel/ed, px, st [Education, Psychology, Standards] (147905)
- 2 exp Allied Health Personnel/ed, px, st [Education, Psychology, Standards] (17230)
- 3 health professional.mp. (5865)
- 4 Nurses/ed, px, st [Education, Psychology, Standards] (10939)
- 5 (Physicians or physician or doctor).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, synonyms] (476625)
- 6 Physicians/ or Physicians, Primary Care/ (80077)

SEARCH CATEGORY 2: Cancer [General]

- 7 Cancer.mp. or Neoplasms/ (1366366)
- 8 exp Neoplasms/nu, px, rh [Nursing, Psychology, Rehabilitation] (53367)
- 9 exp Neoplasms/ (2920483)

SEARCH CATEGORY 3: Prostate Cancer [Specific]

- 10 exp Prostatic Neoplasms/ (108186)
- 11 Cancer of the Prostate.mp. (6223)
- 12 Prostatic Cancer.mp. or Prostatic Neoplasms/ (107276)
- 13 Prostatectomy.mp. or exp Prostatectomy/ (32610)

SEARCH CATEGORY 4: Sexual health / dysfunction / recovery [Male]

- 14 Mens Health.mp. or Men's Health/ (2223)
- 15 Erectile Dysfunction.mp. or Erectile Dysfunction/ (20015)
- 16 Sexual Behavior/ or Reproductive Health.mp. or Reproductive Health/ or "Delivery of Health Care"/ (132144)
- 17 Sexual Dysfunctions, Psychological/ or Adult/ or Sexual Dysfunction, Physiological/ or Middle Aged/ or Sexual Behavior/ or Sexual Dysfunction.mp. (5652673)
- 18 sexual health.mp. or Reproductive Health/ (7171)
- 19 Sexuality/px [Psychology] (1706)
- 20 Erectile Dysfunction/ or Penile rehabilitation.mp. or Penis/ (30035)
- 21 Penile rehabilitation.mp. (131)

SEARCH CATEGORY 5: Other chronic illness

- 22 Chronic disease/
- 23 Lung diseases/ or Adult/ or Pulmonary Diseases, Chronic Obstructive/
- 24 Cardiac disease.mp or Heart diseases
- 25 Diabetes.mp
- 26 HIV/HIV.mp
- 27 Nervous system diseases/ or Multiple Sclerosis/ or Adult/ or neurological diseases.mp
- 28 Musculoskeletal Diseases/ or musculoskeletal conditions.mp.

SEARCH CATEGORY 6: Communication training, aids, tools

- 29 Communication/ or Health Communication/ or Communication Barriers/ (78363)
- 30 Communication/ or health professional.mp. or "Attitude of Health Personnel"/ (176979)
- 31 Decision Making/ or Decision Support Systems, Clinical/ (85172)
- 32 Decision Aids.mp. or Decision Support Techniques/ (16491)
- 33 Decision Support Techniques/ (16019)

- 34 Professional-Patient Relations/ or Physician-Patient Relations/ or patient-provider communication.mp. or Communication/ or Patient Education as Topic/ (216989)
- 35 Adult/ or Communication/ or Physician-Patient Relations/ (4498811)
- 36 Patient Engagement.mp. or Patient Participation/ (21784)
- 37 Counseling/ or Sexual Behavior/ or Sex Counseling/ or Sex Counselling.mp. or Health Knowledge, Attitudes, Practice/ or Adult/ (4485536)
- 38 Health Communication/ or Communication Barriers/ or Communication/ or Communication.mp. (259761)

SEARCH CATEGORY 7: Health professional education

- 39 Education, Continuing/ or Education, Professional/ or Education/ or Education, Medical/ or Health Education/ or Education, Public Health Professional/ or Education, Nursing/ (166348)

SEARCH CATEGORY 8: Study design

- 40 Qualitative Research.mp. or exp Qualitative Research/ (37545)
- 41 Cohort Studies.mp. or Cohort Studies/ (215424)
- 42 Observational Study.mp. or Adult/ or Prospective Studies/ or Observational Study/ or Epidemiologic Methods/ (4648482)
- 43 exp Focus Groups/mt, ut [Methods, Utilization] (557)
- 44 Interview, Psychological/ or Interview/ (41021)
- 45 Qualitative Research/ or Middle Aged/ or Interviews as Topic/ or Adult/ or "Attitude of Health Personnel"/ (5726919)
- 46 Adult/ or Nursing Methodology Research/ or Focus Groups/ (4416583)

Figure 2. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram showing process of selection for systematic review [15]

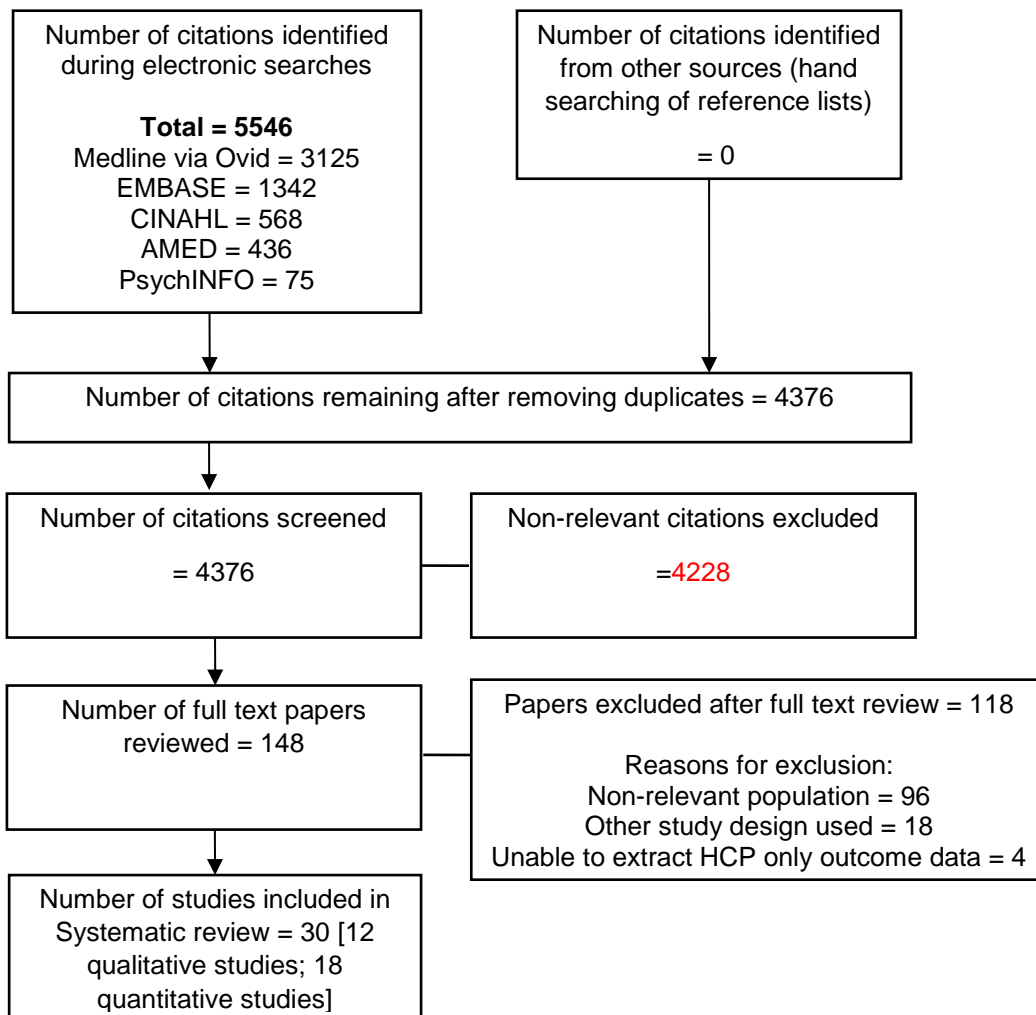


Table 1. Example of how first and second order interpretations from the included evidence [related to how sexuality is defined] were used to develop one third order interpretation which formed part of theme 1 [Attitudes to sexual wellbeing discussion in practice].

| Construct order | |
|--|---|
| <p>First order interpretations [participant quotes reported in the primary studies]</p> | <p>[1] "It [sexuality] is very hard to describe it in a sentence or even a few sentences".</p> <p>[2] "It [sexuality] is not just cut and dry, it is not a simplified sort of thing. It is so complex, because it is not only the physical but the mental and trying to tap into people's mental attitudes and appreciation of where they are at the present can be very difficult".</p> <p>[3] "It can be your gender, your status, your approach to things, your coping mechanism, and an array of things to each individual".</p> <p>[4] "I think it is a very individual thingy I mean the actual scope of sexuality within an oncology setting in particular varies from one person to another. I think sexuality is very individual".</p> |
| <p>Second order interpretations [Interpretations or conclusions made by authors of the primary studies]</p> | <p>[1] How participants defined sexuality varied greatly among the sample. It was evident from the verbal and non-verbal cues of the participants in many of the interviews that they were experiencing difficulty verbalising their understanding of sexuality.</p> <p>[2] All of the participants suggested that sexuality was a multidimensional concept, and an important part of human existence. A number of participants proposed that the meaning that one attributes to sexuality very much depends on the individual.</p> <p>[3] The majority of participants viewed sexuality as much more than a physical concept, instead associating it to a considerable extent with the emotional, psychological and social realms.</p> |
| <p>Third order interpretation [Interpretations made by authors of the meta-synthesis based on overall first and second order interpretations]</p> | <p>[1] Existing social values influence participant views on defining sexuality</p> |
| | <p>This third order interpretation contributed to one of three third order interpretations that were categorised under theme 1 [Attitudes to sexual wellbeing discussion in practice (barriers)]</p> |

Table 2. Characteristics and quality assessment scores of qualitative studies exploring healthcare professional's views on discussing sexual wellbeing with patients

| Study | Country | Participants / setting | Sample size | Aim | Data collection | Analysis method | CASP |
|-------|---------|------------------------|-------------|-----|-----------------|-----------------|------|
|-------|---------|------------------------|-------------|-----|-----------------|-----------------|------|

| | | | | | n method | | score /10 |
|----------------------|-----------|---|------------------------|--|--|--|------------------|
| D'eath et al. 2013 | Ireland | Hospital-based cardiac rehabilitation staff [nurses, care coordinators, social workers, physiotherapists, occupational therapists] | 14 9 [total:33] | To explore experiences of, and beliefs about, sexual assessment and counselling in coronary heart disease | 3 focus groups [60 mins] Semi-structured telephone interview [15 mins] | Interviews transcribed and coded before sorting into categories and themes | 7 |
| Ferreira et al. 2015 | Brazil | Nurses, nursing technicians, nursing assistants working in ward and outpatient settings | 16 | To identify barriers influencing practice related to sexuality of women with gynecological and breast cancer | Individual, face-to-face semi-structured interview [30 mins] | Interviews transcribed and coded into categories using Content Analysis methodology | 4 |
| Horden et al. 2007 | Australia | Hospital based health professionals in cancer and/or palliative care [Medical and nursing staff, social work, occupational therapy, Physiotherapy, Pastoral, Volunteer] | 32 | To present constructions of intimacy and sexuality in cancer to gain insight into the shaping of this taboo in clinical Practice | Semi-structured, face-to-face interviews including feedback from participants attending educational forums | Interviews transcribed, coded and analysed conceptually using Giddens work on sexuality, intimacy and reflexivity as a framework | 8 |
| Lavin et al. 2006 | Ireland | Oncology nurses in chemotherapy day units | 10 | To examine perceptions and experiences in addressing sexuality as an aspect of care to women receiving chemotherapy | Individual, face-to-face interviews | Interviews transcribed and analysed to identify themes which were clustered using the constant comparative method | 5 |

| | | | | for breast cancer | | | |
|--------------------|--------|---|----|---|--|---|---|
| Lindau et al. 2011 | USA | Healthcare providers [nurses, chaplain, social worker, psychologist, surgical oncologist, medical oncologist] | 8 | To explore perspectives on effects of lung cancer on physical and emotional intimacy, ways in which intimacy affect experience of living with lung cancer, and communication about intimacy and sexuality | Semi-structured, one-on-one, in-person interviews based on a grounded theoretical approach [20-60 mins] | Interviews transcribed, coded using qualitative analysis software and analysed using iterative textual analysis | 4 |
| Mellor et al. 2013 | UK | Staff working in hospital, primary care and community settings [Nursing and medical staff, therapist, support coordinator, health care assistant] | 30 | To examine views and experiences of discussing sexual wellbeing with patients who have had a stroke, to identify barriers and suggest improvements to information provision | Face-to-face interviews with individuals, in pairs, or in a three [30 mins] | Interviews transcribed, coded and grouped using an Inductive and constant comparison approach | 8 |
| Olsson et al. 2012 | Sweden | Clinic and ward-based nurses working in cancer care [surgical care, gynecological cancer care, hematological care, oncology, palliative care] | 10 | To describe nurses' conceptions of dialogues about sexuality with cancer patients | Thematic, individual, face-to-face interviews [30-60 mins] | Interviews transcribed and analysed into clusters | 7 |
| Stead et al. 2013 | UK | Medical, surgical and nursing staff in ward and outpatient settings | 43 | To identify level of information provided, opinions on sexual | Semi-structured interviews | Interviews summarised using frequencies and | 2 |

| | | [general and oncological gynaecology] | | issues, and training needs of staff | | qualitative comments | |
|---------------------|-------------|--|----|---|--|--|---|
| Traa et al. 2014 | Netherlands | Healthcare professionals [surgeon, gynecologist, gynecologist/oncologist, urologist, psychologist, physician assistant, nurse practitioner, stoma nurse | 10 | To explore healthcare needs and factors that impede or facilitate sexual health care | Moderated focus groups [HCPs only] [90 mins] | Focus group recordings transcribed, coded and themes identified / grouped using stepwise analysis and a grounded theory approach | 5 |
| Ussher et al. 2013 | Australia | Medical and nursing staff, psychologists, social workers, Working across cancer specialties, [general, gynaecology, haematology, breast, colorectal, neurological, urological] | 38 | To identify how health professionals discursively construct sexuality in the context of cancer; what subject positions do health professionals adopt in relation to sexual communication and barriers to sexual communication | Semi-structured face-to-face and telephone interviews | Interviews summarised and data analysed using a poststructuralist discourse analytic perspective | 6 |
| Vermeer et al. 2015 | Netherlands | Hospital based gynecological oncologists, radiation oncologists, oncology nurses | 30 | To assess healthcare professionals' psychosexual support practices, barriers to providing support, and training and assistance needs in gynecological cancer | Face-to-face [22] and telephone interviews [8] [25 mins] | Interviews transcribed and coded into categories using framework approach | 5 |

| | | | | | | | |
|-------------------|--------|---------------------------------|----|--|----------------------------|--|---|
| Viera et al. 2013 | Brazil | Nursing staff in cancer clinics | 28 | To understand how sexuality of women undergoing treatment of breast cancer is understood | Semi-structured interviews | interviews transcribed and subjected to content analysis and thematic categorization | 5 |
|-------------------|--------|---------------------------------|----|--|----------------------------|--|---|

Table 2. Characteristics and quality assessment scores of quantitative studies exploring healthcare professional's views on discussing sexual wellbeing with patients

| Study | Country | Participants / setting | Sample size (response rate [%]) | Aim | Data collection method | Analysis methods | Interpretation of main findings | Survey checklist score /10 |
|---------------------|---------|--|---------------------------------|---|---|--|---|----------------------------|
| Butler et al. 2001 | Canada | Hospital based oncology nursing staff [surgical, medical, ambulatory care] | 74/155 [47.7] | To examine the practice of sexual health by nurses working in cancer care | Survey on Sexually-Related Nursing Practice (SSRNP) including total score [26-182 points] and seven subscale scores for practice, values, responsibility, confidence, discussion with others, clients. reactions and staffs reactions | Descriptive analysis using mean, SD, range and frequencies | Total scores [103.3; SD: 13.5] and sub-scores indicated respondents perceived sexuality to be an important part of practice and were confident in their own practice but delivery of care did not reflect this | 5 |
| Byrne et al. 2010 | Ireland | Cross sectional sample of General Practitioners | 61/230 [27.0] | To survey experiences of, and attitudes about, discussing sexual health issues with people with CHD | 15 item questionnaire questions developed by authors covering level of knowledge, awareness, confidence, current practice perceived barriers and management [open question]* | Descriptive analysis using means and frequencies | Most respondents had good confidence [41%], and knowledge [62%] but only fair awareness [41%] and rarely or never discussed sexual problems [70%]. Lack of time and patient readiness [72%] were identified as barriers | 4 |
| Doherty et al. 2011 | Ireland | Cardiac coordinators [nurses, physiotherapists and psychologists] | 60/99 [61.0] | To provide knowledge on service provision and develop strategies | 20 item questionnaire [6 to 72 points] developed by authors covering return of sexual activity, delivery of information, guidelines for | Descriptive analysis using means, SD and frequencies | Respondents reported patients are too sick to discuss sexual concerns [76%], do not expect them to ask [67%], and | 6 |

| | | | | | | | | |
|-----------------------|-------------|---|----------------|---|--|---|--|---|
| | | | | and interventions | assessment and counselling, knowledge, awareness and confidence, comfort, questions from Sexual attitudes and beliefs survey (SABS) and perceived barriers* | | were uncomfortable having discussions [57%]. Barriers included lack of confidence (45%), knowledge (58%) and training (85%) | |
| Hautamäki et al. 2007 | Finland | Hospital based Health Professionals [Nursing, radiotherapy, physiotherapy, social work, physician] | 215/300 [72.0] | To describe healthcare professionals' attitudes toward and experiences of discussing sexuality-related issues | 19-item Questionnaire developed from literature including items on discussing sexuality issues, role, who takes the initiative to discuss issue, frequency of discussion, and responsibility for dealing with issues | Frequency distributions and cross tabulations. Stepwise logistic regression to identify influencing factors | Lack of training, a perception that the patient is not ready to discuss sexual health issues, a general lack of knowledge of sexual health issues and issues relating to both culture and language | 6 |
| Helland et al. 2013 | Norway | Health Professionals [nurses, occupational therapists, physicians, physiotherapists, psychologists, & social workers] | 274/647 [42.0] | To explore management of sexual issues in patients with rheumatic diseases | 12 item questionnaire with five point descriptive scales covering current practice, barriers, knowledge and education | Descriptive analysis using multivariate logistic regression model to explore if sexual issues occurred | Respondents perceived sexuality as a relevant topic [96%] but never or seldom raise issues [72%] and thought patients should raise sexually related topics [88%]. Barriers included patient embarrassment [83%] and lack of time [72%] | 6 |
| Hoekstra et al. 2012 | Netherlands | Heart failure nurses | 146 | To examine current practice of discussing sexual health in HF clinics | 2 subscales of the Nurses' Survey of Sexual Counselling of Myocardial Infarction Patients, a list of barriers used by Doherty et al 2011 (see above). 8 | Descriptive analysis using means, SD and percentages. Chi-square | 61% do not assess sexual health, although 74% feel responsible for discussing it. Key barriers were lack of organizational | 5 |

| | | | | | | | | |
|-----------------------|-----------|-------------------------------|-----------------|---|--|--|---|---|
| | | | | | additional items on barriers | tests used to compare the perceived barriers of nurses who do and do not discuss sexual health with their patients | policy, patient factors, [culture, religion, language, ethnicity, severity of illness] | |
| Hordern et al. 2009** | Australia | Oncology health professionals | 155 | To determine if communication training framework can reduce barriers to discussing sexuality, and increase confidence & frequency in discussing sexuality with patients | Questionnaire consisted of 20 items assessing the barriers to discussing sexuality, seven items assessing confidence in discussing sexuality, how often discussed in past 2 months | Descriptive analysis using frequencies | Responses recorded at baseline indicated embarrassment (health professional and patient) (3.11, 3.49); worry about intruding (3.27); not having the right words (3.12) and it not being an area of expertise (3.30) were the greatest barriers to communication | 4 |
| Huang et al. 2011 | China | cancer nurses | 128/150 [85.33] | To investigate practices and attitudes toward sexual issues and determine the factor correlations of attitudes regarding pelvic radiation | 10 item questionnaire developed by authors exploring nurses' responsibilities in dealing with sexual items | Descriptive statistics. Chi square used to investigate the correlations between nurses' attitudes and their demographic data | 88.3% agreed that nurses should have professional knowledge to solve the sexual problem'. 57.8% agreed with 'I feel uncomfortable talking about sex with patients.' | 5 |

| | | | | patients' sexuality in a clinical setting | | | | |
|-------------------------|---------------|--|-----------------|--|---|--|---|---|
| Jonsdottir et al 2016** | Iceland | Oncology nurses and physicians | 136/206 [66%]** | To evaluate the outcomes of a sexual health care educational intervention by comparing the attitudes, practices, and perceived barriers of health care professionals before and after implementing the intervention. | 15 item questionnaire developed by authors covering practice issues and attitudes in relation to sexual health care knowledge, training, resources and barriers | Descriptive statistics used for proportions, means and demographic data. Chi-square test for categorical variables | Participants (90%) regarded communication about sexuality part of their responsibilities. 16% reported discussing sexuality-related issues with more than 50% of patients. Common barriers were "lack of training" (38%) and "difficult issue to discuss" (27%). | 8 |
| Julien et al 2010 | United States | Nurses working in acute care, ambulatory, and perioperative services | 576 | To explore oncology nurses' attitudes about and knowledge of sexual health | Attitudes and beliefs about patients' sexual health assessment in nursing practice were evaluated with the Sexual Attitudes and Beliefs Survey | Descriptive and inferential analysis | Nurses do not think that sexuality is too private an issue to discuss (mean =2.03, SD =1.11) and understand how disease and treatment may affect sexuality (mean= 2.24, SD = 1). Barriers included a perception that patients do not expect nurses to discuss sexual concerns | 3 |

| | | | | | | | | (mean=3.52, SD=1.07) |
|-------------------------|-------------|--|----------------|---|---|---|--|-------------------------|
| Krouwel et al. 2015 (a) | Netherlands | Members of the Dutch Society for Surgical Oncology | 165/437 [37.7] | To evaluate current practice, attitude and opinions of Dutch surgical oncologists towards information provision and communication about sexual issues. | 31-item questionnaire developed by the authors assessing sociodemographic factors, frequency of discussing sexual issues, responsibility for dealing with sexual issues, Knowledge about sexual issues related to surgery, Training needs of surgical oncologists, Barriers in discussing sexual issues | Descriptive analysis using frequencies. Pearson's chi-square test used for Bivariate associations | Surgical oncologists do not routinely discuss sexual issues Common barriers include advanced age, not relevant for all types of cancers and lack of time | 7 |
| Krouwel et al. 2015 (b) | Netherlands | Radiation oncologists, | 119/234 [54.6] | To investigate the attitude, knowledge, and barriers of Dutch radiation oncologists toward informing their patients on the possibility of treatment-induced Sexual Dysfunction. | 28-item questionnaire developed by the authors | Descriptive analysis using frequencies | 75% agreed discussing sexual function is their responsibility. Additional training was required according to 44%. Barriers included patient being too ill (36%), age of patient (27%) and culture/religion (26%) | 6 |
| Krouwel et al. 2015 (c) | Netherlands | Nurses involved with oncology patients | 477 | To investigate nurses' knowledge about and opinions on | 37 item tool developed by author measuring practices, attitudes, content of sexual counselling, responsibility, need for | The results were described using frequency distribution | The majority (87.6%) agreed discussing sexual function is their responsibility and was routinely | 5 |

| | | | | | | | | |
|-----------------------------|---------------|--|--------------|--|---|---|--|---|
| | | | | the responsibility for addressing SF in oncology treatment settings in The Netherlands, and to look at their attitudes to the subject and identifying what they consider as barriers to addressing it. | education and barriers regarding discussing SF and fertility issues | | performed by 33.4%. Barriers included lack of training, presence of a third party and no motive for initiating discussions. | |
| Leonardi-Warren et al. 2016 | United States | Clinical Oncology HCPs | 95 | To explore whether clinical oncology HCPs have adequate knowledge and are comfortable addressing sexual health issues | Survey covering attitudes (17 items) related to discomfort, uncertainty, fear, environmental support and practices (21 items) related to sexual function, psychological factors, social problems and reproductive care. | Data were analyzed using descriptive statistics and tests of difference and association | A majority reported that sexual health concerns were important to patients (n = 89, 84%) but most reported discomfort discussing sexual health issues with patients (n = 86, 60%). Around half the participants (n = 86, 56%) believed that patients would be uncomfortable discussing sexual issues | 6 |
| Moore et al. 2013 | Ireland | registered staff nurses, clinical nurse managers, clinical nurse | 89/200 [45%] | To investigate oncology nurses self- | 71 item questionnaire devised by the authors divided into four sections (demographics, | Frequencies and descriptive statistics | Respondents were open to addressing concerns but few informed patients | 7 |

| | | | | | | | | |
|--------------------|--------|---|-------------------------|--|---|--|---|---|
| | | specialists and advanced nurse practitioners | | perceived knowledge and comfort in relation to discussing sexuality concerns with men diagnosed with testicular cancer and to identify the barriers and facilitators to such discussions | perceived barriers to discussing sexuality issues, items that might facilitate discussion, and a free text section for any other comments | were calculated for each variable. | they were available to discuss sexual concerns. Nurses reported lacking knowledge of, and discomfort in, discussing intimate aspects of sexuality. | |
| Oskay et al. 2014 | Turkey | Oncology nurses | 87 | To determine, the views and attitudes of nurses caring for cancer patients towards sexual counselling. | Questionnaire was developed by the authors and included demographic questions, sexual health in cancer and questions regarding counselling | Descriptive analysis using means, median, minimum and maximum values and percentages. | Most do not evaluate sexual problems (88.5%). Key barriers included absence of routine regarding sexual counseling, a belief that patients may become ashamed and insufficient skills and education | 7 |
| Wang et al. 2015** | USA | Oncologists, surgeons, nurses/other allied health | 71/89 [79% survey 1]*** | To test the hypothesis that brief, targeted, female sexual health training would result in improved provider comfort level | 8-item survey to assess knowledge of female cancer-related sexual issues, perceived access to sexual health resource/referrals, comfort level and self-reported frequency of addressing breast cancer-related sexual issues | Non-parametric Mann-Whitney test used to compare mean scores over time and Chi-Square tests used | 85% of respondents agreed women with cancer were interested in sexual health information, but less than 50% felt comfortable bringing up and coordinating care, and less than 25% actively | 8 |

| | | | | | | | | |
|--------------------|-------|-----------------|-----|--|--|--|---|---|
| | | | | and frequency of addressing female cancer related sexual issues. | | for comparison of response distribution | addressed sexual health for the majority of patients | |
| Zeng et al. 2011** | China | Oncology nurses | 199 | To describe Chinese nurses' attitudes and beliefs regarding sexuality care in cancer patients and to explore relevant demographic factors influencing nurses' views of sexuality care. | Chinese version of the 12-item Sexuality Attitudes and Beliefs Survey (SABS) | Descriptive analysis mean, SD and percentages. | (76.4%) perceived sexuality as too private an issue to discuss and 63.8% assumed patients lacked interest in sexuality because of their illnesses. Most (77.9%) did not make time to discuss sexuality issues with patients, and nearly 70% did not feel confident and comfortable discussing concerns. | 8 |

* Single open questions not included in qualitative analysis

** Interventional studies exploring pre-post training views. Data extracted at baseline only

*** Data extracted for baseline responses only

CHD: Coronary Heart Disease; HF: Heart Failure; SD: Standard Deviation

Table 4. GRADE-CERQual framework table

| Review theme | Methodological limitations [Number of satisfactory studies] | Relevance [partial or direct evidence] | Adequacy [number of key concepts] | Coherence [Number of studies out of 30] | Overall assessment of confidence |
|--|--|---|--|--|---|
| 1. Attitudes to sexual wellbeing discussion in practice (barriers) | 14 | 14 Direct 1 Indirect | 3 | 15 | Moderate |
| 2. Patient factors (barriers) | 24 | 22 Direct 2 Indirect | 14 | 26 | Moderate |
| 3. Organizational and professional factors (barriers) | 27 [All] | 27 Direct | 17 | 27 | High |
| 4. Overcoming barriers and using tools (facilitators) | 9 | 10 Direct 1 Indirect | 4 | 11 | Low |
| 5. Training needs and support (facilitators) | 12 | 12 Direct 2 Indirect | 4 | 14 | Moderate |
| | | | | Overall assessment of confidence | Moderate |

Table 5. Concepts extracted from included evidence and third order themes derived during meta-synthesis

| Third order interpretations | Second order interpretations | Key supporting evidence |
|--|---|---------------------------------------|
| 1. Attitudes to sexual wellbeing discussion in practice (barriers) [n=3] | <ul style="list-style-type: none"> - Myths and assumptions around age, gender, partner status - Social values - Cultural norms | 31,32,35,38,41*,48* |
| 2. Patient factors (barriers) [n=14] | <ul style="list-style-type: none"> - Sensitivity of topic - Role of patient's partner (relationships) - Differences in age, gender, sexuality impacting discussions around sexual issues - Recognition of possible change in sexual function and wellbeing due to illness - Condition specific needs - Influence of phase of care - Sexual wellbeing and function not seen as a priority - Uncertainty over initiating conversations (professional role) - Uncertainty over initiating conversations (setting) - Issues around body image and identity - Sexual activity being discouraged - Cultural norms and values of patients - Expectations and hopes - Patient information needs | 31,33,36,38,52*,53* |
| 3. Organizational and professional factors (barriers) [n=17] | <ul style="list-style-type: none"> - Lack of time in the clinical setting - Sensitivity of topic - Lack of support options to offer patients - Lack of area knowledge - Different communication style or approach - Uncertainty over initiating conversations (professional role) - Unclear referral and support options - Focus on biomedical approaches and sexual function - Lack of confidence in area - Wishing to not become involved in complex issues around patient's relationships - Unmet patient needs - Lack of practical resources | 33,35,36,38,39,44*,45*,48*,49,56*,58* |

| | | |
|---|---|----------------------|
| | <ul style="list-style-type: none"> - Lack of continuity of care - Unclear professional roles - Uncertainty around method of delivery of support (group or 1-to-1 settings) - Location, setting and timing to discuss sexual wellbeing - Influence of staff gender | |
| 4. Overcoming barriers and using tools (facilitators) [n=4] | <ul style="list-style-type: none"> - Interdisciplinary communication and support including referral routes - Use of active listening - Provision of brief, limited information to normalise sexual wellbeing discussion - Use of brief, tools or systems to integrate sexual wellbeing into holistic care | 33,34,36,38,43*,52* |
| 5. Training needs and support (facilitators) [n=4] | <ul style="list-style-type: none"> - Use and training in models of sexual care assessment and support - Use of peer mentoring or support - Introduction into undergraduate and post-graduate education - Training in communication skills | 38,40,41,45*,43*,57* |

* Derived from quantitative evidence