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## Review article

# Conceptualising quality of life outcomes for women participating in testing for sexually transmitted infections: A systematic review and meta-synthesis of qualitative research

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## ABSTRACT

Many public health interventions have aims which are broader than health alone; this means that there are difficulties in using outcome measures that capture health effects only, such as Quality Adjusted Life Years (QALYs). Sexually Transmitted Infections (STIs) are a major public health concern both in the UK and globally, with *Chlamydia trachomatis* being the most common bacterial STI worldwide. There is scope for the wider use of qualitative syntheses in health-related research; in this study we highlight their potential value in informing outcome identification, particularly for public health interventions where a broad range of outcomes may need to be considered. This article presents a systematic review and meta-ethnography of qualitative studies that investigated women's experiences of thinking about and participating in testing for chlamydia. The meta-ethnography highlights issues relating to beliefs about STIs and testing, assessing risk and interpreting symptoms, emotional responses to testing, coping with diagnosis, relationship with sex partners(s), informal support, and interaction with health care services. The study findings suggest that women can experience a range of impacts on their health and quality of life. It is important that this range of effects is taken into account within evaluations, to ensure that decision makers are fully informed about the outcomes associated with screening interventions, and ultimately, to make sure that appropriate interventions are available to support women in maintaining good sexual health.

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## 1. Introduction

As health care resources are scarce, the benefits of alternative interventions or programmes often need to be identified, measured, valued and compared alongside their costs (Drummond et al., 2005). Many decision-making bodies prefer the effects (or benefits) of interventions to be measured in the form of Quality Adjusted Life Years (QALYs) (e.g. National Institute for Health and Care Excellence (NICE), 2013; Pharmaceutical Benefits Advisory Committee, 2008). However, there are difficulties in applying this approach to evaluations of public health interventions (Edwards et al., 2013; NICE, 2012). The use of QALYs necessarily implies that the objective of the intervention is to maximize health (Mooney, 2003). Many public health interventions aim to affect

broader aspects of quality of life which means that measuring outcomes in terms of QALYs alone may miss important intervention effects (Lorgelly et al., 2010).

Sexually Transmitted Infections (STIs) are a major public health concern globally, with *Chlamydia trachomatis* (chlamydia) being the most common STI in the UK (Public Health England., 2015). Because STIs such as chlamydia are frequently asymptomatic, screening is recommended in many countries; however more evidence is required about the effectiveness and cost-effectiveness of such interventions (Low et al., 2009; Jackson et al., 2014). There is a paucity of standardised tools and guidance about how outcomes should be measured for those accessing sexual health services and about which aspects of health and quality of life should be considered (World Health Organisation, 2010; Stephens et al., 2013).

Exploration of the existing evidence is recommended to identify appropriate outcome measures (Streiner and Norman, 2008). Methods of qualitative synthesis can help to overcome some of the potential limitations associated with narrative literature reviews which can be viewed as susceptible to bias and unsystematic

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(Campbell et al., 2011). Methods for synthesising qualitative evidence are relatively new and there is scope for their wider use within health-related research (Al-Janabi et al., 2008; Bennion et al., 2012; Campbell et al., 2011); in this paper we highlight their potential value in informing outcome identification.

A rich body of research exists which explores people's experiences of thinking about the possibility of having an STI and participating in testing. We undertook a synthesis of these qualitative studies to identify key concepts and themes, to identify appropriate outcomes in STI screening for curable diseases such as chlamydia. Our objective was to explore women's experiences of thinking about the possibility of being at risk and undergoing testing/screening for an STI, and to examine any reported impacts on their health and quality of life. The study addressed these questions primarily through the lens of chlamydia infections and their sequelae. However, this emphasis was not exclusive as chlamydia is often linked with other STIs, and evidence suggests that public knowledge about specific STIs is limited (Chaudhary et al., 2008). We focused on women's experiences of thinking about and participating in STI testing as guidance suggests that gender is a critical factor to take into account when planning, implementing and evaluating interventions in this area (National Chlamydia Screening Programme, 2009).

## 2. Methods

As qualitative syntheses represent a relatively new research area, there are no agreed guidelines about how they should be undertaken and a range of approaches are possible (Campbell et al., 2011). We adopted the approach of meta-ethnography (Noblit and Hare, 1988) as adapted to health research by Britten et al. (2002). Meta ethnography is an interpretative approach which involves the 'translation' of studies into each other (Britten et al., 2002). This involves comparing the concepts and their interrelationships in one study with those in another study, whilst respecting original meanings and context. The aim is to generate new theoretical understandings which allow us to better understand the 'whole (organization, culture etc.) based on selective studies of the parts' (Noblit and Hare, 1988, p. 62). Ethical approval was not required for this study as it involved the review and synthesis of existing qualitative studies.

### 2.1. Systematic search and screening

A search was conducted of six electronic databases: MEDLINE, EMBASE, CINAHL, Web of Science, PsycINFO, and Sociological Abstracts from 2000 to the end of June 2013 by LJ with support from TR (an example of a search strategy is given in Appendix 1). This was supplemented by hand searching of key journals and references. The SPICE framework (a generic model for question formulation) was used to guide the literature searching (Booth and Brice, 2004):

- Setting: primary care, sexual health centres, or general community settings
- Perspective: young women (primarily aged 18–35)
- Intervention: thinking about or undergoing testing for STIs
- Comparison: other health concerns, accessing other types of testing/screening
- Evaluation: attitudes, views, beliefs, emotions, symptoms

We used a three stage process to identify studies for inclusion (Roberts et al., 2002). Initially, papers were screened using the title and abstract to identify potentially relevant papers. Papers were then sorted into five groups (A to E) according to the STIs they were

concerned with (Table 1). Papers which were labelled as concerned with experiences of testing for curable STIs (Category A) or potentially relevant (Category D) were analysed further. Those mainly concerned with incurable STIs such as HPV and HIV (Categories B and C) were excluded, as evidence suggests that the perceived permanence of these diseases plays an important role in women's experiences of receiving a positive diagnosis (Nack, 2008). Next, the full texts of potentially relevant studies were read and they were classified into six further groups based on the methods used to conduct the research and whether primary or secondary data was reported (Table 1). We included studies with a variety of epistemological frameworks and examined study perspective as part of our analysis.

### 2.2. Critical appraisal

Once potential studies for inclusion had been identified, they were appraised using a modified version of the CASP (Critical Appraisal Skills Programme) checklist. We used an approach outlined by Dixon-Woods et al. (2007), which involves assessing the relevance and value of papers to the synthesis, rather than using reporting quality to exclude papers (Bennion et al., 2012; Campbell et al., 2011; Malpass et al., 2009). Using this method, a double review was undertaken, whereby we independently assessed whether papers were 'key papers' (KP) which meant that they were valuable to the synthesis, 'satisfactory papers' where they were less conceptually rich but still potentially valuable (SAT), or whether we were 'unsure' (?) about the value of the paper to the synthesis. A sensitivity analysis was undertaken to examine the impact of excluding papers on the basis of reporting quality.

### 2.3. Translating and synthesising the studies

Initially we read and re-read the papers in chronological order and recorded details about each study in a data extraction form. Alongside information about the study context and methodology, we also extracted second order constructs we identified within the studies, illustrating them with first order constructs (Malpass et al., 2009). This was done independently by the authors. First order constructs are patients' views and interpretations of their experiences as reported in direct quotations; second order constructs are the study authors' interpretations of patient views, and third order constructs represent the interpretations of the synthesisers (Bennion et al., 2012). Working definitions of first and second order concepts were developed, which were subsequently adapted. We created a grid of common and recurring second order concepts (key concepts), which we then completed with the second order interpretations from each paper, illustrated with first order constructs, and included relevant details about the study setting (Britten et al., 2002; Malpass et al., 2009). The grid was used collaboratively to understand how the studies were related to each other and analyse the second and first order constructs (Bennion et al., 2012; Malpass et al., 2009; Shaw, 2011). By comparing the concepts within the papers and our interpretations of them, a 'reciprocal' relationship between the studies became evident (Noblit and Hare, 1988). We then continued the process of translating the studies into one another and further developed the 'key concepts' to ensure that they fully encompassed the concepts described in the original papers. We developed third order concepts using a 'line of argument' approach which involved considering the translations of the studies and bringing them together to construct an over-arching interpretation (Britten et al., 2002; Campbell et al., 2011). This process was led by LJ, with TR working independently to check and confirm the third order concepts.

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