Qual Life Res (2009) 18:423–433
DOI 10.1007/s11136-009-9459-1

Continence specialists use of quality of life information in routine practice: a national survey of practitioners

**Kirstie L. Haywood · Andrew M. Garratt ·
Sandra Carrivick · Joanne Mangnall ·
Suzanne M. Skevington**

Accepted: 15 February 2009 / Published online: 7 March 2009

Abstract

Objectives To survey continence specialists (CSs) about their assessment practice including their use of quality of life (QoL) information, perceived barriers, benefits and training needs.

Methods Cross-sectional national postal survey of 624 practicing CSs in the UK. The questionnaire included open and closed questions relating to assessment practice.

Results Completed questionnaires were returned by 299 (49%) CSs. Although 80% routinely assessed QoL, fewer than 54% demonstrated awareness of published questionnaires. The majority used structured questions (41%) many of which were non-standardised single items (26%) or locally developed questionnaires (19%). Only 22% used standardised patient-completed questionnaires such as the King's Health Questionnaire and the Incontinence Quality of Life questionnaire. Perceived assessment barriers included the availability of appropriate questionnaires, patient disability, limited guidance, resources and time. Of those routinely assessing QoL, 77% wanted more support; the most useful media cited being the internet, followed by professional guidance and training courses.

Conclusion Although QoL measurement is highly valued, there was wide variation in assessment practice with few adopting standardised approaches. Most CSs require greater guidance and support that takes account of their diverse needs. Familiar assessment barriers exist which the use of web-based information, in association with professional guidance might help overcome. Clear mechanisms are required to direct standardised and appropriate assessment practice.

Keywords Routine practice · Health professionals

Background

Continence problems affect the health and quality of life (QoL) of the individual across a range of concerns, including physical, social and emotional issues [1, 2]. Although complex, a review of continence-related symptoms and the associated impact on health and QoL has been recommended as a key component of assessment practice for people with continence problems in the UK [3, 4]. While recommendations for the assessment of symptoms exist, for example [5, 6], limited guidance is available for healthcare practitioners to support the mechanisms by which QoL should be assessed. Furthermore, little is known about how these recommendations have been implemented within routine practice.

Electronic supplementary material The online version of this article (doi:10.1007/s11136-009-9459-1) contains supplementary material, which is available to authorized users.

K. L. Haywood (✉) · S. Carrivick
Royal College of Nursing Research Institute,
School of Health and Social Studies, University of Warwick,
Coventry CV4 7AL, UK
e-mail: k.l.haywood@warwick.ac.uk

A. M. Garratt
National Resource Centre for Rehabilitation in Rheumatology,
Diakonhjemmet Hospital, PO Box 23 Vinderen, 0139 Oslo,
Norway

J. Mangnall
Rotherham Primary Care NHS Trust, Doncaster Gate Hospital,
Rotherham S65 1DU, South Yorkshire, UK

S. M. Skevington
WHO Centre for the Study of Quality of Life, Department of
Psychology, University of Bath, Bath BA2 7AY, UK

Although more informal, non-standardised approaches to enquiring about an individual's quality of life are widely adopted in routine clinical practice [7–10], standardised approaches to assessing QoL, more recently referred to as patient-reported outcome measures (PROMs) [11], have been developed over recent years [12–14]. PROMs are largely self-completed questionnaires' containing multiple questions to measure a wide range of health-related concepts such as pain, physical disability, treatment satisfaction or quality of life. Increasingly, well-developed PROMs are viewed as an essential part of healthcare assessment, providing a rigorous approach to assessment and an accessible and meaningful mechanism by which patients may communicate the impact of ill-health and associated health care [15–17]. Structured reviews of PROMs can provide some guidance for questionnaire selection, and are available in continence care [18, 19].

While the use of PROMs in clinical research settings is widely accepted, e.g. [20], there is less certainty surrounding the application of PROMs in routine practice [16, 21]. Several surveys have explored the views of medical doctors about QoL assessment and the inclusion of PROMs in routine practice, and while the use of standardised PROMs is generally low, most respondents are very positive about the assessment of QoL and potential use of PROMs [7–10]. Importantly, potential benefits from the team-use of QoL information following patient-completion of PROMs have been identified, including the supporting of shared decision-making, communication and the appropriate evaluation of treatment success [7]. Others suggest that nurses may place greater value in the assessment of QoL than other medical colleagues [16, 22].

However, it is unclear how nurses, and more specifically continence specialists (CSs), assess QoL in routine practice, and if they are adopting more reliable means of QoL assessment through the appropriate use of well-developed, standardised PROMs. The current study provides an opportunity to explore the assessment practice of continence specialists. The study objectives were:

(1) To describe the current assessment practice of UK continence specialists, including the methods adopted and influencing factors, when assessing QoL.
(2) To assess the perceived benefits and barriers relating to the routine assessment of QoL and to explore ways to facilitate assessment practice.

This will determine the extent to which guidance for good practice in continence assessment has been adopted. Furthermore, knowledge of the perceived incentives, barriers and benefits in assessing QoL in routine practice are necessary to inform training, education and future research that are designed to increase and improve QoL assessment.

Methods

Sampling

The Continence Foundation is a charitable trust with the most comprehensive database of continence services provided by UK health authorities, and was used to identify UK-based CSs. The database is updated annually following requests from the Continence Foundation to all continence service providers (Dr Judith Wardle, Director, personal communication, August 2005), and is representative of UK CSs. At the time of the survey, the database listed 683 healthcare professionals (nurses and physiotherapists) who formed the sampling frame for the study. The national survey of practicing CSs was conducted by contacting all specialists listed on the Continence Foundation database (updated April 2006 www.continence-foundation.org.uk/). (The Continence Foundation was officially replaced by the Bladder and Bowel Foundation in September 2008 http://www.bladderandbowelfoundation.org/).

For inclusion, CSs must have been registered with the Continence Foundation and have worked in the 4 weeks prior to the start of the survey. Retired and non-practicing continence care specialists were excluded.

Survey questionnaire

Questionnaire development followed a review of earlier surveys relating to the use of QoL data and PROMs in routine practice [7–10, 22, 23], research exploring barriers to the utilisation of research evidence in practice [24–26], published reviews of continence-specific outcome measures [18, 19, 27] and a review of good practice for the conduct and design of questionnaire surveys in healthcare [28]. Three researchers (K.H., A.G., S.S.), experienced in the measurement of patient-reported outcomes and previous surveys relating to the use of QoL data, were responsible for developing and reviewing questionnaire items.

The questionnaire sought quantitative information through closed-format questions amendable to statistical analysis, and qualitative information in the form of open-format questions to explore areas of uncertainty [7, 28, 29]. Questions addressed current assessment practice, focusing on the assessment of QoL, and explored the following concepts: (1) clinicians' views about QoL assessment, including perceived benefits and barriers to assessment; (2) what QoL data are routinely collected and the methods adopted; and (3) the use, and factors influencing use, of collected QoL data.

Questionnaire pre-testing and pilot evaluation

Pre-testing of the questionnaire involved a convenience sample of ten CSs who participated in a focus group to assess the content validity of the questionnaire and identify any ambiguities. For example, ‘patient completed structured question(s) or questionnaire’ was seen as preferential to the term ‘patient-reported outcome measure’. Following modifications, the same ten CSs participated in individual telephone interviews with cognitive debriefing supporting further modifications. The pilot evaluation involved a postal survey of 15 CSs, randomly selected from the Continence Foundation database using a random numbers table. Comments were sought on questionnaire content, relevance and ease of understanding resulting in some minor modifications.

The final questionnaire comprised 31 questions: 7 covered general assessment practice and 12 QoL assessment (see Supplementary data). The remaining 12 questions related to demographic, employment and patient case-load related issues. These questions formed part of a longer questionnaire (not presented) with an additional 13 items covering the assessment of symptoms, patient-identified goals and patient satisfaction with health care (available on request).

The survey was mailed with a reply-paid envelope. Those not wishing to participate were asked to return the questionnaire blank. Non-respondents were sent a reminder letter at 2 weeks and a further questionnaire at 4 weeks.

Data analysis

Descriptive statistics were computed for closed-format questions. Exploratory content analysis guided the extraction of qualitative themes for the open-ended questions which were analysed using a ‘framework’ analysis [30].

Results

Sample characteristics

There were 299 respondents to the questionnaire giving a corrected response rate of 49% after those who were ineligible or unreachable were deducted from the 658 approached. Fourteen questionnaires (2.0%) were returned uncompleted. The demographic and employment characteristics of the respondents are shown in Table 1. The majority had a nursing background and had been working as a CS for between 6 and 10 years. The majority of respondents provided care for adult patients, but there was considerable variation in patient characteristics (Table 1).

Clinicians’ views about QoL assessment

All clinicians thought that assessing the impact of symptoms on a person’s QoL was of moderate to extreme importance [Question (Q) 8], and almost 60% were extremely interested in QoL assessment (Q9). The majority assessed symptoms (89.0%) and QoL (83.3%) in 75% or more of their patients (Q1). A very small minority assessed symptoms (0.3%) or QoL (2.3%) in fewer than 10% of their patients. Fewer than 2% indicated that they had thought about assessing QoL but were unlikely to do so in the

Table 1 Respondent characteristics ($n = 299$)

Variable	*n*	%
Gender		
Female	293	98.0
Male	6	2.0
Age (years)		
Mean	45.9 (SD 7.9)	
Range	26–69 years	
Clinical background		
Nursing	279	93.9
Physiotherapy	20	6.4
Years in practice ($n = 294$)		
<1 year	0	0.0
1–5 years	1	0.3
6–10 years	11	3.7
11–15 years	43	14.4
16–20 years	54	18.1
>20 years	183	61.2
Years as a continence specialist ($n = 291$)		
<1 year	6	2.0
1–5 years	34	11.7
6–10 years	115	39.5
11–15 years	65	22.3
16–20 years	44	15.1
>20 years	27	9.3
Involved in audit ($n = 256$)		
Current	159	53.2
Previous	88	29.9
Never	9	3.5
Involved in research ($n = 230$)		
Current	5	22.6
Previous	119	51.7
Never	59	25.7
Time with patient contact		
<60%	166	55.7
>60%	132	44.3
Client groups		
Adults	283	95.3
Older people	276	92.3
Children	144	48.5
Communication difficulties	244	82.2
Learning difficulties	262	88.2
First language non-English	203	68.4

foreseeable future (Q10). None of the respondents stated that they had not or had barely thought about assessing QoL.

Clinicians were asked to rank the QoL dimensions they would prioritise when assessing a patient with continence problems from (1) most important to (5) least important (Q11) (Table 2). Physical health (35%), emotional health (34%) and normal role activities (23%) were ranked as the most relevant dimensions. Although rarely ranked as the primary dimension of interest, more than 60% ranked social well-being in the top three dimensions. Despite achieving the lowest rank, single item measures of global well-being were reportedly the most widely used in routine practice.

Clinicians were asked to indicate who or what had influenced their decision to assess the impact of continence problems and health care, such as symptoms or QoL, in their routine practice (Q4) (Table 3). Published continence research, training courses and communicating the impact of practice were the most likely factors to influence assessment practice. These influences were followed by professional guidance, personal experience, recommendations by peers or colleagues and participation in research or audit. Recommendations by management were perceived to be unlikely to influence assessment practice.

Benefits of QoL assessment in routine practice

Although the nature of QoL assessment was not specified, responses to an open-format question about the perceived benefits of QoL assessment (Q15) described six main benefits, including ensuring an accurate diagnosis, assisting in clinical decision-making, planning and delivery of individualised care plans, treatment and management, to give a baseline to monitor progress and measure effectiveness of the treatment or management plan, to understand the patient's perspective and communicate with the patient, and involving or engaging the patient or carer in the identification of goals and enhancing compliance.

Monitoring progress and measuring the effectiveness of care were widely reported benefits of QoL assessment. This

Table 2 Quality of life domains considered important by clinicians for routine continence assessment ($n = 299$)

QoL dimensions[a]	*n*	Mean (1 = high)	% Ranking dimension as most important (1)						
			1st	2nd	3rd	4th	5th	6th	7th
Psychological or emotional well-being—including anxiety and depression	271	2.08	34.0	35.4	20.0	9.6	0.6	0.4	–
Physical health—including ability to undertake ADL	276	2.16	34.8	31.2	20.0	12.0	1.8	–	0.4
Normal role activities/independence	266	2.95	23.0	12.0	21.8	34.5	7.5	0.8	0.4
Social well-being—including personal relationships	271	3.10	6.6	20.7	34.3	33.6	4.1	0.4	0.4
Environmental	266	5.30	0.8	2.0	2.0	6.4	52.1	24.8	12.0
Spiritual health	258	5.98	–	0.4	0.8	1.2	20.9	50.8	26.0
Global well-being	258	6.21	3.1	0.4	1.6	2.3	11.6	22.1	58.9

[a] Question 4: *Who or what* has influenced your decision to assess the impact of continence problems and healthcare, such as symptoms and quality of life, in your routine practice?

Table 3 Factors influencing assessment of continence-related QoL ($n = 299$)

Factors influencing QoL assessment[a]	Mean (SD)	Median (inter-quartile range)	'Extremely' or 'quite a bit' *n* (%)	'Moderately' or 'a little bit' *n* (%)
Published continence research	3.98 (0.94)	4.00 (3.00, 5.00)	213 (71.2)	68 (22.7)
Training courses	3.94 (0.94)	4.00 (3.00, 5.00)	201 (67.2)	82 (27.4)
The need to communicate to others the impact of my practice	3.90 (0.98)	4.00 (3.00, 5.00)	197 (65.9)	76 (25.4)
Guidance from a professional body	3.60 (1.30)	4.00 (3.00, 5.00)	153 (51.2)	62 (20.7)
Personal experience	3.43 (1.30)	4.00 (2.00, 4.00)	162 (54.2)	94 (31.5)
Recommendations by peers/colleagues	3.52 (0.98)	4.00 (3.00, 4.00)	155 (51.9)	113 (37.8)
Participation in research/audit	3.41 (1.15)	4.00 (3.00, 4.00)	149 (49.8)	110 (36.8)
Published literature reviews of questionnaires	3.39 (1.15)	4.00 (3.00, 4.00)	144 (48.1)	114 (38.1)
Recommendations by management	2.41 (1.25)	2.00 (1.00, 3.00)	58 (19.4)	132 (44.1)

[a] Question 4: *Who or what* has influenced your decision to assess the impact of continence problems and healthcare, such as symptoms and quality of life, in your routine practice? Item response options: Not at all (1), A little bit (2), Moderately (3), Quite a bit (4), Extremely (5)

was perceived as providing a holistic patient assessment, enhancing clinician understanding and providing a focus for patient involvement with patients being motivated to contribute to the developing care plan. Several clinicians indicated that the assessment added credibility to the healthcare process, providing an indication of a good result for both patient and clinician. They also suggested that this in turn enhanced patient compliance and contributed to the developing relationship between patient and professional.

Although the target of the communication was not specified, when asked how they communicated to others, including managers and other health professionals, the impact of their care on patient outcome (Q5), the majority of clinicians reported general discussion without formal presentation of data (65.5%, $n = 196$). Fewer than 40% present the results from structured questions or questionnaires that demonstrate the impact of care on symptoms ($n = 114$, 38.5%) or QoL ($n = 86$, 29.1%). Little information relating to the specific questions or questionnaires used was given. The minority communicate the impact of care via audit of symptomology (14.4%, $n = 43$) and/or QoL (9.4%, $n = 28$).

Barriers to QoL assessment in routine practice

Clinicians were asked to indicate those factors limiting their assessment of QoL in routine practice (Q16) (Table 4). Responses to a closed-format item highlighted patient disabilities, the availability of appropriate questionnaires, limited resources or time, and limited guidance as the most likely barriers. These factors remained most influential when those clinicians reporting a 'moderate' influence on assessment practice were included.

A subsequent open-format question (Q17) asked clinicians to indicate those factors they considered the greatest barriers to QoL assessment in routine practice (Table 5). These barriers included difficulties in communication, dissatisfaction with the available assessment questionnaires and lack of time. Clinician-perceived patient factors including embarrassment and unwillingness to disclose important information early on in the care relationship, together with clinician-based factors including lack of confidence and limited understanding of the concept of QoL, were additional contributing concerns.

What QoL data is collected and how?

When asked about the type of information clinicians perceived to be most useful to assessment practice (Q3), responses to an open-ended question suggested that patient-reported information in relation to their daily routine, lifestyle and more general QoL was seen as complimentary to more traditional approaches to assessment. The latter included information from clinical investigations, physical examination, a symptom profile (onset, duration, severity and pattern), medical history (obstetric history and sexual dysfunction) and information relating to the use of medication and products related to continence problems. However, actual collection of QoL information was most often secondary to the more traditional symptom-dominated, biomedical assessment.

Clinicians were asked how QoL was assessed by a question (Q13) describing a hierarchy continuum of formal usage starting with formal, patient-completed structured question(s) or questionnaires and ending with a general discussion about QoL. Responses were not exclusive and most clinicians used information from more than one category. The small majority of 149 (51%) clinicians reported making informal records about QoL informed by general discussion. Just 34 (12%) reported that QoL was discussed but not recorded. Structured questions were used to record QoL information by 123 (41%) of clinicians and, where described (26%), these were often single items: many used a rating scale to show how 'bothersome' the condition was. Other clinicians indicated the use of a variety of locally developed single items (6.6%).

Table 4 Factors limiting assessment of continence-related QoL in routine practice ($n = 299$)

Factors limiting QoL assessment[a]	Mean (SD)	Median (inter-quartile range)	'Extremely' or 'quite a bit' *n* (%)	'Moderately' or 'a little bit' *n* (%)
Patient disabilities—e.g. communication difficulties	2.61 (1.00)	2.00 (2.00, 3.00)	60 (20.1)	196 (65.5)
Appropriate questionnaires are not available	2.35 (1.27)	2.00 (1.00, 3.00)	64 (21.4)	130 (43.5)
Limited resources or time to assess QoL	2.30 (1.07)	2.00 (1.00, 3.00)	42 (14.5)	176 (58.9)
Limited guidance to inform assessment	2.20 (1.02)	2.00 (1.00, 3.00)	39 (14.0)	169 (56.5)
Limited knowledge about assessing QoL	1.92 (0.87)	2.00 (1.00, 2.00)	19 (6.3)	172 (57.5)
Limited understanding about how information would be used	1.82 (0.90)	2.00 (1.00, 2.00)	17 (5.7)	148 (49.5)
Limited confidence in assessing QoL	1.80 (0.88)	2.00 (1.00, 2.00)	14 (4.7)	151 (50.5)

[a] Question 16: Do the following factors *limit* your assessment of *quality of life* in routine practice? Item response options: Not at all (1), A little bit (2), Moderately (3), Quite a bit (4), Extremely (5)

Table 5 Open-format responses to perceived barriers to QoL assessment in continence routine practice ($n = 299$)

Perceived barriers to QoL assessment[a]	
Communication difficulties	Language barriers, disability or non-communicative patients
Appropriate assessment tool	Difficulty in selecting or identifying an appropriate assessment tool, questionnaire or 'trigger' questions
	Dissatisfaction with available questionnaires
Lack of time	Limited time to conduct a full assessment (patient examination, elicitation of symptoms, information on QoL)
	Limited time to build a rapport with the patient
Patient factors	Embarrassment, non-disclosure
	Patient as poor historian
	Difficulties understanding the questionnaires
	Loss of insight to how their lives are affected by their incontinence
Practitioner factors	Limited knowledge or training; lack of confidence in QoL assessment
	Other staff or carers not viewing incontinence as a problem
	Other staff not completing the necessary paperwork
The concept 'quality of life'	Limited understanding of the concept of QoL
	How to assess QoL?
	Challenges of dealing with the emotional impact on patients when discussing QoL issues; the need for additional resources or training when sensitive issues are raised
Resource issues	General lack of resources to support appropriate QoL assessment

[a] Question 17: In your opinion, what are the *greatest barriers* to the assessment of *quality of life* in your routine practice?

Just 55 (20%) clinicians reported using clinician-completed questions. However, 13 reported using clinician-completion versions of patient-completed PROMs such as the Kings Health Questionnaire (KHQ) [31] ($n = 7$) and the Incontinence Quality of Life questionnaire (I-QoL) [32] ($n = 2$). Ten reported using clinician-completed items within the Continence Care Pathway usually in the form of a single item 'bothersome' scale [33]. Locally developed assessment tools or single item assessments were reported by 18 clinicians.

Only 71 (24%) used patient-completed questions. Although further information was obtained for 61 cases, only 34 (11.4%) of all respondents identified named a particular questionnaire, the most widely used being the KHQ. Seven (2.3%) reported the use of single questions adapted from the Continence Care Pathway [33], which was often a single item 'bothersome' scale. Nineteen (6.3%) used locally developed questions or questionnaires. Almost 24% ($n = 17$) of those clinicians who reported using patient-completed questions also used clinician-completed questions to gain further QoL information; 54% included structured questions ($n = 38$).

Clinicians were asked about their awareness and/or use of named questionnaires in research, audit or routine practice (Q19). The list included five generic measures of QoL, and ten condition-specific measures informed by recommendations for use when evaluating continence-related therapies [27]. Fewer than 54% of clinicians were aware of any of the listed questionnaires, including single item questions for the assessment of QoL or general well-being.

However, 30 clinicians who had previously indicated that patient-completed question(s) or questionnaires were *not* used to assess QoL in routine practice (Q13) reported use of selected named questionnaires. Therefore, in total, 64 (21.5%) clinicians reported the use of standardised questionnaires or PROMs in routine practice, the majority of whom used only one PROM ($n = 41$), the most widely used being the KHQ ($n = 10$). The majority of these clinicians were currently ($n = 23$) or had previously been ($n = 22$) involved in research or audit.

The most widely known generic measure was the WHOQOL [34] (43%), followed by the SF-36 [35] (32%) and the EuroQoL [36] (24%). However, the SF-36 was most widely used in research or audit (3%, $n = 9$) and routine practice (2%, $n = 6$).

The most widely known specific measure was the KHQ which 40% ($n = 117$) of clinicians were aware of, 7.4% ($n = 22$) had used it in research, and a further 7.4% ($n = 22$) reported using it in routine practice. More than 30% of clinicians also reported being aware of the International Continence Society Quality of Life questionnaire (ICS-QoL) [37] (34%, $n = 101$), the Bristol Female Lower Urinary Tract Symptom questionnaire (BFLUTS) [38] (32%, $n = 95$) and the Incontinence Impact Questionnaire (IIQ) [39] (31%, $n = 91$).

How is QoL data used?

Clinicians were asked to indicate the extent to which they used QoL information, however gathered, to inform a range of activities in routine practice (Q14). Responses to this closed-format question indicated that the majority of clinicians used QoL information to enhance patient involvement, improve patient adherence and satisfaction with care, monitor the effectiveness of care and measure patient outcome (Table 6). More than 50% used QoL information to help with clinical decision-making and to communicate to others the impact of practice on patient outcome.

Of the 269 (89%) clinicians who regularly assessed QoL, 209 (77.7%) required support to enable them to do so more effectively, whereas 60 (22.3%) do not (Q10). In response to an open-ended question about reducing barriers to the assessment of quality of life in routine practice (Q18), various strategies were suggested. The development of a nationally accepted patient-completed questionnaire or assessment form was considered most important with a call for more training, guidance and information to increase practitioner knowledge and empathy when addressing QoL issues. To a lesser extent, CSs suggested the following: longer consultation times; improved organisation of pre-assessment information gathering—including the pre-empting of patient communication difficulties; greater utilization of a team approach to assessment; changed attitudes towards QoL issues within NHS organizations; more informal, appropriate and private assessment areas; and more training and information for patients and carers.

Clinicians ranked routes for the provision of information from most preferred (1) to least preferred (5) (Q7). Clinicians reported easy access to web-based information as the most preferential route (44.7%). Guidance from a professional body and training courses were ranked second and third, respectively, with more than 50% of clinicians ranking professional guidance as first or second in importance. Although relatively few clinicians ranked access to health care libraries as the primary route of information, more than 60% ranked it amongst the top five sources of information.

Discussion

In advocating the routine assessment of both symptoms and continence-related QoL issues, current good practice guidance in the UK recognises the wide ranging impact of continence problems in terms of physical, emotional and social problems [1, 2]. However, little guidance exists to support the assessment of QoL and little is known about the implementation of these recommendations. This survey provides a timely appraisal of current assessment practice, with specific reference to QoL assessment by CSs in routine practice. It also highlights the perceived benefits, barriers and, more importantly, future challenges for assessment practice.

The 49% of CSs who responded to the survey demonstrated substantial interest in the assessment of QoL, suggesting that this value is widely shared among these specialists. Furthermore, all indicated that QoL assessment, however conducted, was important to routine practice. In addition, the majority indicated that QoL assessment formed a routine part of their assessment practice. The greatest perceived benefits related to the ability to involve patients more readily in the consultation, enhance patient adherence and satisfaction with care, and monitor the effect of care on patient outcome.

However, there is little evidence, even among those who think it is important, that CSs are using standardised questions or questionnaires to assess QoL. Fewer than 22% report using a standard multi-item questionnaire. Most of those who assessed QoL did so in a relatively unstructured

Table 6 Use of continence-related QoL information in routine practice (*n* = 299)

Use of QoL information[a]	Mean (SD)	Median (inter-quartile range)	'All of the time' or 'a very great extent' *n* (%)	'A moderate extent' or 'a small extent' *n* (%)
Involve patients in the consultation	4.16 (0.84)	4.00 (4.00, 5.00)	240 (80.3)	46 (15.4)
To improve patient adherence and satisfaction with care	4.07 (0.91)	4.00 (4.00, 5.00)	226 (75.6)	55 (18.4)
To measure patient outcome	4.05 (0.96)	4.00 (4.00, 5.00)	221 (73.9)	58 (19.4)
To monitor the effectiveness of care	4.02 (0.88)	4.00 (4.00, 5.00)	225 (75.2)	60 (20.0)
To help clinical decision-making	3.63 (1.00)	4.00 (3.00, 4.00)	166 (55.5)	43 (14.4)
To communicate to others the impact of practice on patient outcome	3.50 (1.14)	4.00 (3.00, 4.00)	149 (49.8)	114 (38.1)
To help with diagnosis	3.04 (1.15)	3.00 (2.00, 4.00)	97 (32.4)	157 (52.5)

[a] Question 14: To what extent do you *use* information about *quality of life* in the following activities? Item response options: Not at all (1), A small extent (2), A moderate extent (3), A very great extent (4), All of the time (5)

way (51%), used single questions (41%) or locally developed non-standardised questions or questionnaires (13%). Well-developed PROMs provide a rigorous, standardised method by which relevant information can be elicited, recorded, monitored over time and shared with other members of the healthcare team including the patient, supporting the regular monitoring of treatment progress. Although the rapport generated between a clinician and patient is clearly important, non-standardised approaches to assessment may have little value beyond that perceived by the individual clinician [9]. Moreover, where locally developed methods of assessment lack appropriate evidence for important measurement properties, such as reliability and validity, this undermines confidence relating to score interpretation, the comparison of scores between patients and communication of scores between health professionals. The high level of interest in QoL assessment and associated relatively low uptake of standardised approaches to assessment has been reported by others including oncology clinicians [8, 9, 40] and UK-based general practitioners [7].

The discrepancy between clinicians who initially indicated that patient-completed structured question(s) or questionnaires were not used in routine practice, but nonetheless reported the use of selected questionnaires when these were explicitly listed, may suggest that the respondent misunderstood the initial question, answering in the negative because they were unsure of what constituted a ‘patient-completed structured question(s) or questionnaire’, but when prompted by a list of such questionnaires were able to report on their use of one or more. Although extensive questionnaire pre-testing suggested that use of the term ‘questionnaire’ was acceptable to potential respondents, further definition may have improved clarity and reduced any potential ambiguity. Alternatively, an initial response of lack of use may represent the ‘true’ situation, the subsequent report of using a particular questionnaire representing an invalid response, perhaps indicative of social desirability bias [28, 41].

The list of perceived barriers to QoL assessment included concern over the availability and appropriateness of questionnaires, patient disabilities, limited resources or time and limited guidance. The perceived lack of appropriate questionnaires may be a function of a lack of awareness of available questionnaires, with fewer than 54% of clinicians recognising any standardised questionnaire from a list informed by recent recommendations for application in continence research [27] and earlier reviews of PROMs [18, 19]. Alternatively, many PROMs were originally developed for clinical research, and clinicians may perceive that such measures lack relevance to routine practice and individual assessment. The diversity of the patient population cared for by the participating health professionals, in terms of disability, age and first language, were additional factors influencing the perceived inappropriateness and poor acceptability of certain questionnaires.

A large number of clinicians indicated that the time required for QoL assessment was a barrier to assessment practice. It was apparent that assessment practice was dominated by a traditional ‘medical model’ approach to information gathering whereby clinician generated documentation, investigations and symptom-dominated assessment preceded exploration of the patient perspective, including the identification of patient goals, expectations from care and satisfaction. Evidence from this survey suggests that clinicians value the usefulness of QoL information alongside symptom-related information. However, little time was often available for subsequent QoL assessment, as symptoms take priority. Although evidence of symptoms is informative to diagnosis and clinical decision-making, enabling patients to effectively communicate their personal experience of ill-health, and their expectations, needs and values relating to healthcare is central to patient-centred care [42]. The emotional and physical well-being elements of QoL were rated as most important to continence-related QoL assessment, with global or general assessment having least relevance. However, in practice, few CSs formally assessed emotional or physical well-being. The majority assessed global well-being or bothersomeness via a single question, often drawn from the Continence Care Pathway [33]. Although single questions have the benefit of simplicity and minimal respondent burden, they provide a very limited picture of such a complex construct as QoL, are less reliable than multi-item questionnaires, and their interpretation is difficult as lower symptoms intensity does not necessarily mean better QoL [36]. Moreover, evidence from oncology suggests that, counter to popular clinical opinion, assessing QoL using standardised PROMs does not add time to the clinical encounter [43].

To avoid the perception of increased burden, the introduction of standardised QoL assessment into routine practice may require some ‘trade-off’ with more traditional approaches to assessment being replaced by more informative QoL measures or application of PROMs. Many clinicians lacked knowledge and confidence in the more standardised assessment of QoL, and to jettison familiar methods of assessment in favour of something new, irrespective of the evidence-base, requires significant support and guidance [44]. Moreover, as observed by others [7], the use of standardised questionnaires to elicit patient information is not a standard component of healthcare practice, the traditional assessment of body structure and function being far more familiar.

Various suggestions were made by clinicians to facilitate the incorporation of QoL assessment into routine practice. Underpinning this was the need for appropriate training and support. The provision of web-based facilities with accessible information about QoL assessment, supported by guidance from professional bodies and associated training courses, were the major recommendations. Associated with this was the call for a nationally agreed, standardised assessment form, the development of which considered the needs of the diverse patient group and embraced a patient-centred, multi-disciplinary team approach to assessment.

Three factors, reported to be critical to the success of incorporating QoL data into routine practice, support these findings: (1) the definition of an acceptable core set of measures that are also known to have good psychometric properties; (2) the selection of measures that have clinical relevance; and (3) the acceptance of formal assessment by clinicians and patients [45]. The clinical relevance of selected measures, supported by training and support to encourage a positive attitude to the usefulness of formal assessment, should facilitate staff acceptance. Where more formal assessment becomes a regular part of assessment practice supported by knowledgeable clinicians, patient acceptance is also facilitated. Moreover, in order to accept the incorporation of more standardised QoL assessment into the care process, patients and clinicians must have an understanding of how measurement can enhance the clinician patient interaction, the health care process more generally and, ultimately, patient outcomes including patient experiences and quality of life [17].

The appropriate timing of the QoL assessment was raised as an important challenge to assessment practice. Continence problems often result in sensitive and embarrassing concerns, and patients need time to build trust and rapport before real concerns are disclosed to health professionals. Several clinicians reported that real problems were not communicated until several treatment sessions had elapsed. There is growing evidence that PROMs may further enhance communication between patients and health professionals [17, 43]. A well-developed QoL questionnaire could act as a trigger to raising important issues earlier in the consultation or assessment process, supporting the communication of patient important outcomes and priorities. Further empirical work to explore the role of PROMs in this context is required [17, 21].

With advancing technology, electronic data capture of PROMs may enhance the feasibility of application, whilst the real-time provision of scores may enhance the utility of application in routine practice. However, this national survey clearly highlighted the challenge of limited resources in supporting change in assessment practice. The reality is that few practices currently have access to facilities to capture and archive data electronically. No clinician reported access to electronic data-capture systems, and many work in relative isolation in community settings. Standardised QoL assessment supports the identification of patients with the greatest needs, which in turn supports the provision of more timely and appropriate interventions to address these needs. Demonstrating the cost effectiveness of incorporating QoL assessment into routine practice is essential to good practice [46], and to attracting appropriate resources to support more efficient data capture.

An acceptable response rate was achieved, which was comparable to other surveys of healthcare professionals [7, 9, 22]. In comparison to the 4-page questionnaire reported by Skevington et al. [7], the current study incorporated a 12-page questionnaire. The response rate suggests that the topic was of interest to clinicians, but the length and required time for completion may have deterred potential respondents. Moreover, respondents may reflect those with very strong positive or negative views on QoL assessment which may affect the levels of usage reported [28]. Data were self-reported and it was not possible to determine actual assessment practice. However, other authors have suggested that expressed willingness to undertake an activity is strongly related with actual use [8]. Descriptive information, including demographic and care-setting mix, about non-responders was not available and hence must be considered a further limitation of the study. The questionnaire included both closed and open-ended items, and in several sections, open-ended items followed linked closed items (see Supplementary data). Responses to open-ended questions can be shaped by preceding closed questions on similar topics [28], and responses to the linked items in this survey produced similar conclusions. However, the open-ended questions supported further exploration of CS-reported barriers to the assessment of QoL in routine practice. Less widely reported issues included patient embarrassment, an unwillingness to disclose sensitive information early on in the care relationship, and limited understanding of the concept of QoL.

The measurement and communication of ill-health and the consequence of healthcare interventions are essential components of nursing practice and wider health care [47]. Although providing an insight into the views and experience of CSs, the results of the survey may have relevance to other specialist nurse practitioners, particularly those working with patients with chronic, long-term conditions. However, the views and experiences of other nurse specialists and allied health professionals, providing care for different groups of patients, require further exploration. Following appropriate refinements and amendment to content, the study questionnaire should be considered as a basis for informing future surveys of assessment practice.

As with other surveys of medical practitioners, this survey shows that CSs are positive about the assessment of QoL, but few adopt, or are familiar with, standardised approaches to QoL measurement. The relative disjunction between the CSs belief in the importance of QoL assessment and actual assessment practice was highlighted: CSs want to assess QoL but most often do not know how to select an appropriate questionnaire and some would like more technical support to do so effectively. A range of familiar barriers exist, magnified by the diversity of the patient population encountered. Key challenges to traditional symptom-based assessment include effectively embracing patient-centred care with a re-evaluation of assessment practice where formal, standardised QoL assessment is valued as an integral part of care. It is essential that mechanisms are put in place to support clinicians in appropriate assessment practice.

References

1. Norton, N. J. (2004). The perspective of the patient. *Gastroenterology, 126*, S175–S179. doi:10.1053/j.gastro.2003.10.081.
2. Miner, P. B., Jr. (2004). Economic and personal impact of fecal and urinary incontinence. *Gastroenterology, 126*, S8–S13. doi:10.1053/j.gastro.2003.10.056.
3. Department-of-Health. (2000). Good practice in continence services. UK Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005851. Accessed 2 Mar 2009.
4. Scottish-Intercollegiate-Guidelines-Network SIGN 79. (2004). *Management of urinary incontinence in primary care. A national clinical guideline*. Edinburgh: Scottish-Intercollegiate-Guidelines-Network.
5. Winder, A. (1996). Assessment and investigation of urinary incontinence. In C. Norton (Ed.), *Nursing for continence* (2nd ed., pp. 33–75). Beaconsfield: Beaconsfield Publishers Ltd.
6. Getliffe, K., & Dolman, M. (1997). Normal and abnormal bladder function. In K. Getliffe & M. Dolman (Eds.), *Promoting continence: A clinical and research resource* (pp. 22–67). London: Bailliere Tindall.
7. Skevington, S. M., Day, R., Chisholm, A., & Trueman, P. (2005). How much do doctors use quality of life information in primary care? Testing the trans-theoretical model of behaviour change. *Quality of Life Research, 14*, 911–922. doi:10.1007/s11136-004-3710-6.
8. Bezjak, A., Ng, P., Skeel, R., Depetrillo, A. D., Comis, R., & Taylor, K. M. (2001). Oncologists' use of quality of life information: Results of a survey of Eastern Cooperative Oncology Group Physicians. *Quality of Life Research, 10*, 1–13. doi:10.1023/A:1016692804023.
9. Morris, J., Perez, D., & McNoe, B. (1998). The use of quality of life data in clinical practice. *Quality of Life Research, 7*, 85–91. doi:10.1023/A:1008893007068.
10. Bellamy, N., Kaloni, S., Pope, J., Coulter, K., & Campbell, J. (1998). Quantitative rheumatology: A survey of outcome measurement procedures in routine rheumatology outpatient practice in Canada. *The Journal of Rheumatology, 25*, 852–858.
11. Burke, L., Stifano, T., Dawisha, S. (2006). *Guidance for industry—patient-reported outcome measures: Use in medical product development to support labelling claims*. Rockville, MD: U.S Department of Health and Human Sciences, Food and Drug Administration.
12. Garratt, A., Schmidt, L., Mackintosh, A., & Fitzpatrick, R. (2002). Quality of life measurement: Bibliographic study of patient assessed health outcome measures. *British Medical Journal (Clinical Research Ed.), 324*, 1417–1421. doi:10.1136/bmj.324.7351.1417.
13. McDowell, I. (2006). *Measuring health: A guide to rating scales and questionnaires* (3rd ed.). New York: Oxford University Press.
14. Bowling, A. (1995). *Measuring disease: A review of disease-specific quality of life measurement scales*. Buckingham: Open University Press.
15. Ganz, P. A. (2002). What outcomes matter to patients: A physician-researcher point of view. *Medical Care, 40*, III11–III19. doi:10.1097/00005650-200206001-00003.
16. Greenhalgh, J., Long, A. F., & Flynn, R. (2005). The use of patient reported outcome measures in routine clinical practice: Lack of impact or lack of theory? *Social Science and Medicine, 60*, 833–843. doi:10.1016/j.socscimed.2004.06.022.
17. Haywood, K., Marshall, S., & Fitzpatrick, R. (2006). Patient participation in the consultation process: A structured review of intervention strategies. *Patient Education and Counseling, 63*(1–2), 12–23. doi:10.1016/j.pec.2005.10.005.
18. Naughton, M. J., Donovan, J., Badia, X., Corcos, J., Gotoh, M., et al. (2004). Symptom severity and QoL scales for urinary incontinence. *Gastroenterology, 126*, S114–S123. doi:10.1053/j.gastro.2003.10.059.
19. Symonds, T. (2003). A review of condition-specific instruments to assess the impact of urinary incontinence on health-related quality of life. *European Urology, 43*, 219–225. doi:10.1016/S0302-2838(03)00045-9.
20. Fitzpatrick, R., Davey, C., Buxton, M. J., Jones, D. R. (1998). Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment 2,* I–Iv, 1–74.
21. Marshall, S., Haywood, K., & Fitzpatrick, R. (2006). Impact of patient-reported outcome measures on routine practice: A structured review. *Journal of Evaluation in Clinical Practice, 12*(5), 559–568. doi:10.1111/j.1365-2753.2006.00650.x.
22. Gough, I. R., & Dalgleish, L. I. (1991). What value is given to quality of life assessment by health professionals considering response to palliative chemotherapy for advanced cancer? *Cancer, 68*, 220–225. doi:10.1002/1097-0142(19910701)68:1<220::AID-CNCR2820680140>3.0.CO;2-H.
23. Meadows, K. A., Rogers, D., & Greene, T. (1998). Attitudes to the use of health outcome questionnaires in the routine care of patients with diabetes: A survey of general practitioners and practice nurses. *The British Journal of General Practice, 48*, 1555–1559.
24. Funk, S. G., Champagne, M. T., Wiese, R. A., & Tornquist, E. M. (1991). Barriers to using research findings in practice: The clinician's perspective. *Applied Nursing Research, 4*(2), 90–95.
25. Estabrooks, C. A. (1999). Mapping the research utilization field in nursing. *Canadian Journal of Nursing Research, 30*(4), 273–294.
26. Gosling, S. A., Westabrook, J. I., & Spencer, R. (2004). Nurses' use of online clinical evidence. *Journal of Advanced Nursing, 47*(2), 201–211. doi:10.1111/j.1365-2648.2004.03079.x.
27. National Institute of Health and Clinical Excellence (NICE). (2006). Guideline. Urinary incontinence: The management of urinary incontinence in women. Draft for consultation. http://guidance.nice.org.uk/page.aspx?o=311453. Accessed 2 Mar 2009.
28. Dillman, D. A. (2000). *Mail and internet surveys. The tailored design method* (2nd ed.). Chichester: John Wiley and Sons Inc.
29. McColl, E., Jacoby, A., Thomas, L., et al. (2001). Design and use of questionnaires: A review of best practice applicable to surveys of health service staff and patients. *Health Technology Assessment, 5*(31).
30. Ritchie, J., & Spencer, L. (1994). Chapter 9. Qualitative data analysis for applied policy research. In A. Bryman & R. G. Burgess (Eds.), *Analyzing qualitative data*. London: Routledge.
31. Kelleher, C., Cardozo, L. D., Khullar, C., & Salvatore, S. (1997). A new questionnaire to assess the quality of life of urinary

incontinence women. *BJOG, 104*, 1374–1379. doi:10.1111/j.1471-0528.1997.tb11006.x.

32. Patrick, D. L., Martin, M. L., Bushnell, D. M., Yalcin, I., Wagner, T. H., & Buesching, D. P. (1999). Quality of life of women with urinary incontinence: Further development of the incontinence quality of life instrument (I-QoL). *Urology, 53*, 71–76. doi:10.1016/S0090-4295(98)00454-3.
33. Bayliss, V., & Slater, L. (2004). Pathways for evidence-based continence care. *Nursing Standard, 19*(9), 45–51.
34. The WHOQol Group. (1994). The development of the World Health Organisation Quality of Life Assessment Instrument (The WHOQoL). In J. Orley & W. Kuyken (Eds.), *Quality of life assessment: International perspectives* (pp. 41–47). Berlin: Springer-Verlag.
35. Ware, J. E. (1997). *SF-36 Health Survey Manual and Interpretation Guide. The medical outcomes trust*. Boston, USA: Nimrod Press.
36. The EuroQol-Group. (1990). EuroQol—A new facility for the measurement of health-related quality of life. The EuroQol Group. *Health Policy (Amsterdam), 16*, 199–208. doi:10.1016/0168-8510(90)90421-9.
37. Donovan, J. L., Kay, H. E., Peters, T. J., et al. (1997). Using ICSQoL to measure the impact of lower urinary tract symptoms on quality of life: Evidence from the ICS-"BHP" study. International Continence Society—Benign Prostate Hyperplasia. *British Journal of Urology, 80*, 712–721.
38. Jackson, S., Donovan, J., Eckford, B. S., Swithenbank, L., & Abrams, P. (1996). The Bristol Female Lower Urinary Tract Symptoms Questionnaire: Development and psychometric testing. *British Journal of Urology, 77*, 805–812.
39. Shumaker, S. A., Wyman, J. F., Uebersax, J. S., McClish, D., & Fantl, J. A. (1994). Health-related quality of life measures for women with urinary incontinence: The incontinence impact questionnaire and the urogenital distress inventory. *Quality of Life Research, 3*, 291–306. doi:10.1007/BF00451721.
40. Taylor, K. M., Macdonald, K. G., Bezjak, A., Ng, P., De Petrillo, A. D. (1996). Physician's perspective on quality of life: An exploratory study of oncologists. *Quality of Life Research, 5*, 5–14. doi:10.1007/BF00435963.
41. Streiner, D., & Norman, G. (2003). *Health measurement scales: A practical guide to their development and use* (3rd ed.). Oxford: Oxford Medical Publications.
42. Hibbard, J. H. (2003). Engaging healthcare consumers to improve the quality of care. *Medical Care, 41*, I-61–I-70. doi:10.1097/00005650-200301001-00007.
43. Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P., Brown, J. M., et al. (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial. *Journal of Clinical Oncology, 22*, 714–724. doi:10.1200/JCO.2004.06.078.
44. Haywood, K. L. (2006). Patient-reported outcome I: Measuring what matters in musculoskeletal care. *Musculoskeletal Care, 4*(4), 187–203. doi:10.1002/msc.94.
45. Jacobsen, P. B., Davis, K., Cella, D. (2002). Assessing quality of life in research and clinical practice. *Oncology (Williston Park), 16*(9, Suppl 10), 133–139.
46. Varni, J. W., Burwinkle, T. M., & Lane, M. M. (2005). Health-related quality of life measurement in pediatric clinical practice: An appraisal and precept for future research and application. *Health and Quality of Life Outcomes, 16*(3), 34. doi:10.1186/1477-7525-3-34.
47. Bellamy, N. (2005). Science of assessment. *Annals of the Rheumatic Diseases, 64*(Suppl 2), ii42–ii45. doi:10.1136/ard.2004.031567.