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A STUDY TO INVOLVE OLDER CONTINENCE SERVICE USERS IN THE DEVELOPMENT OF QUALITY STANDARDS IN CONTINENCE SERVICES

The Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians of London completed a national project to define and pilot quality indictors for continence services using national expert working groups and multi-professional panels in 2004. The CEEU recognises the importance of involving older people in the development of standards and the importance attached to this by the Department of Health (DoH 2000). This study was commissioned to involve older continence service users aged 60 and over and their carers in this process of developing standards of care.

Hypothesis / aims of study

To involve, identify and incorporate the views of older continence service users and their carers in the development of standards of care in continence services.

Study design, materials and methods

This three year study was completed in April 2007, had full ethical approval and consisted of three stages combining qualitative and quantitative methods.

- Stage I was concerned with finding out from two focus groups of continence service users in inner-city and rural areas what factors constituted good standards of care and asking their opinions of standards already put forward by professionals in the previous CEEU national project. Factors identified by users were formed into statements, blended to those developed by professionals, and organised into a questionnaire that sought to measure degrees of importance attached to different standards. The questionnaire also included a section on characteristics of the population group, such as continence symptoms and quality of life indicators, formed in consultation with the focus groups.

- The purpose of stage 2 was to conduct a self-completed survey of 300 older continence service users using the questionnaire developed in stage 1 to test the inclusiveness of the standards statements and the importance attached to them. The survey also gave the opportunity to start to ascertain whether degrees of continence symptoms and quality of life factors had a bearing on how standards were rated.

- Stage 3 was concerned with targeting groups of users who were underrepresented in the survey, to ensure their views about standards were included. As the sample in stage 2 consisted largely of women in their 70's, the selection in this stage focused on men over 60 and frail older people and their carers. A total of 80 people in two contrasting areas were targeted using the survey as the instrument to conduct semi-structured interviews.

Results

Stage 1: Standards statements generated from users in the focus groups were concerned with access to buildings, assessment, continuity, information, prognosis and equipment such as pads. Users concurred with the expert panel standards that focused on characteristics of staff, treatment issues, and privacy and dignity. A total of 25 statements were taken forward to stage 2.

Stage 2: A response rate of 55% was achieved (n=155). Standards of particular importance related to the characteristics of staff, such as being seen face-to-face by friendly and approachable specialist staff, who possessed good communication skills. Least important standards related to assessments of respondents' sex lives and being able to choose the gender of the person assessing them. Those rating their health as 'poor' attached greater importance to assessment and being able to get into the building easily. No new service features important to respondents were revealed.

Stage 3: Recruitment difficulties were encountered with this stage; a total of 46 frailer people and their carers took part. Most important standards related to privacy, communication between agencies and being assessed by a caring professional. Least important statements also related to being able to choose the gender of the person assessing them, and assessment of sex lives. The large number of qualitative responses received underlined the emotional and physical impact of continence problems and highlighted the importance of maintaining dignity. The issue of continence pads with respect to comfort, delivery and disposal also featured strongly.

Interpretation of results

Although the response rate was low for stages 2 and 3 it was slightly higher than is usually achieved in general health surveys to this age group. It was clear that most statements were important to respondents particularly those attached

to service delivery issues such as personal qualities of staff and training. This is not an uncommon finding in surveys of this kind with older people. Of interest was the finding that lower importance is placed on the assessment of sex lives which may be of greater relevance to professionals than the continence sufferers themselves. Also, most people in the study were unconcerned about the gender of the assessor. This is contrary to other studies surveying this generation which report that older people prefer to have physical assessments conducted by professionals of their own gender hence indicating a shift in our study. Overall, the study seemed to indicate that the blending of expert panel opinions with user opinions facilitated the development of a series of meaningful standards that were understandable by a range of older people with differing abilities and severity of condition.

Concluding message

The clear impact that the continence condition had on the lives of the respondents came through strongly in the data and it is evident that standards of care in continence services must be sensitive to this. Overall, the standard statements developed in this study with users seemed to reflect this sensitivity as no new statements could be added to the original list of 25. It provided an indication of the relevance of standards to this sample group across different age spans over 60 years and sites. This questionnaire will now be taken forward to a national survey to test the relevance of the standard statements to a much wider audience.

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