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Victorian Stroke Network

Sexuality after stroke A report on the 2013 SOX Program – Executive Summary

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Background and context

Research has demonstrated that physical and psychological changes to sexuality after stroke can have a significant impact on quality of life. Despite this, sexuality is reported to be one of the most neglected parameters that determine quality of life after stroke. This has been attributed to the lack of education for clinicians and the reluctance of clients to raise the issue until they are given permission to do so by clinicians.

To address this gap the National Stroke Foundation (NSF) developed a set of evidence based Guidelines. Guideline 8.5 states that: *stroke survivors and their partners should be offered the opportunity to discuss issues relating to sexuality with an appropriate health professional; and written information addressing issues relating to sexuality post stroke.* The NSF has also developed an information sheet on sexuality and relationships. The NSF monitors compliance with the Guidelines by auditing medical records in stroke services. In 2010 the audit identified that only 12% of stroke survivors were provided with information on sexuality and this figure rose to 17% in 2012.

About the SOX Program

The SOX Program was a collaboration between the Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University and the Victorian Stroke Network (VSN). It involved six half day workshops facilitated between 2012 -2014. The aim of the Program was to build the confidence and capacity of clinicians in the VSN to implement Guideline 8.5, or to provide clients and their partners with written information addressing sexuality after stroke. To achieve this, SOX participants were supported to: critique the evidence; undertake a needs analysis; build organisational support for their project; implement service improvements; and evaluate the outcomes of their project.

Participating organisations were required to identify at least two project researchers from at least two disciplines to attend all the workshops. Ethics approval to work with project researchers and conduct a staff survey was obtained from the Human Research Ethics Committee at La Trobe University.

Principles underpinning the Program principles

- 1) Sexuality: broader than 'just sex' and inclusive of clients across the life span and inclusive of lesbian, gay, bisexual, transgender or intersex (LGBTI) clients.
- 2) Critical sexuality studies: empowering project researchers with resources to gather research evidence to inform service improvements
- 3) Systemic change: acknowledging that change in this area is complex and requires an interdisciplinary approach

- 4) Sexuality after stroke was considered the responsibility of all members of the interdisciplinary team.

Program participants

Sixteen project researchers were appointed and included: six occupational therapists; three clinical neuropsychologists, two social workers, a clinical nurse consultant, a clinical psychologist, a physiotherapist, a rehabilitation consultant and a speech pathologist. The services included community based rehabilitation and a range of inpatient rehabilitation services from five metropolitan and one rural health service.

Findings – program logic

The findings are presented in the form of a program logic model to outline our understanding of ‘what it takes’ to achieve compliance with Guideline 8.5.

1. Aim

The development of project aims for each project was considered important to ensure that project researchers developed a shared understanding with their colleagues about what the project involved.

2. Resources

Undertaking change in this area was time intensive and project researchers had heavy caseloads. The time taken to engage support for the project was expected to be significant, given that the project addressed the values and beliefs of staff. However, an unexpected resource was the time taken to obtain ethics approval in each of the participating health services. There appeared to be concern that the project researchers wanted to talk to clients about sexuality and one service took close to a year to obtain ethics approval.

3. Activities

Eight core activities were identified and are summarised in the following section.

3.1: Establish project supports

Project researchers were encouraged to identify organisational supports to ensure the success and sustainability of their projects. This included high level support such as meetings with managers and senior executives as well as establishing working parties and ensuring peer support. Project researchers benefited significantly where there research support was provided by their organisation.

3.2: Obtain ethics approval

Each participating organisation sought ethics approval to interview clients, audit medical records and survey staff. In two organisations the project researchers had the support of a research mentor, making the application process relatively simple. However, the process was complex and protracted in the remaining organisations because of the lack of internal guidance and the project coordinators lack of experience in ethics applications. It also appeared that the delays in obtaining ethics approval related to ethics committee concerns that clients were being interviewed about sexuality.

3.3: Conduct needs analysis

Once project supports were in place and ethics approval was obtained, a needs analysis was conducted. This created momentum for change and informed service improvements. The needs analysis generally included an organisational audit, medical record audit, staff survey and client interviews.

Organisational audit

An organisational audit tool was developed to ensure that the complex, systemic nature of health services was taken into account. Most project researchers conducted the SOX audit prior to the implementation of their project and scores ranged between 0-3 out of a total possible score of 20, indicating low levels of support for change. One repeated their audit after 10 months and noted an improvement from 0/20 to 15/20, indicating significant improvements.

Medical record audit

A medical record audit was conducted in three services to determine how often information on sexuality was provided and what information was provided. Samples of between 10-20 medical records revealed compliance rates between 0-5%. In one organisation the medical record audit was completed almost a year after the project had commenced and it was noted that compliance with Guideline 8.5 had increased from 5% to 35%.

Staff survey

A staff survey was developed to measure staff knowledge; confidence and comfort. The SOX Survey was undertaken in five sites and completed by 154 staff. Response rates varied significantly from 36 - 83%. Statistical analysis was limited to frequency and descriptive statistics.

- Most survey participants were female (84%) and nurses (28%), physiotherapists (16%) and occupational therapists (16%), doctors (10%), speech pathologists (10%), social workers (7%), psychologists (6%) and three were dieticians.
- 64% indicated that changes to sexuality after stroke would be an issue for younger clients
- 40% indicated that changes to sexuality after stroke would be an issue for older clients
- Overall psychosocial factors impacting on sexuality after stroke were rated as more significant than physical factors
- 80% agreed that providing sexuality after stroke is important
- 41% neither agreed nor disagreed that providing this information was their responsibility and 13% indicated it was not their responsibility
- The responsibility was considered to belong to doctors (92%), followed by psychologists (74%), nurses (67%) and occupational therapists (65%), social workers (56%), physiotherapists (52%), speech pathologists (32%), and dieticians (16%).
- Only 3% rated their confidence as high and 40% reported having little or no confidence.
- 54% reporting that they felt neither comfortable, nor uncomfortable

The quantitative data and qualitative comments from the survey provided valuable information for the project researchers on the need for education and service improvements.

Client interviews

Client interviews were conducted in all the participating organisations to inform strategies for service improvement. Clients were given a copy of the NSF Fact Sheet and invited to talk broadly about the fact sheet or discuss their own experiences and needs. Several clients expressed their relief at the opportunity to discuss sexuality and provided practical suggestions about how sexuality could be addressed. Additionally, clients reiterated the importance of an interdisciplinary approach to sexuality after stroke, with several reporting that the discipline most appropriate to discuss sexuality with was the discipline they had built the most rapport with.

3.4: Provide staff education

Project researchers were provided with resources to deliver education to their colleagues and encouraged to include data from their needs analysis in their education. The education built staff knowledge, confidence and comfort as well as helped to identify strategies for service improvement.

3.5: Document interdisciplinary roles (and communication strategies)

A Guide to Interdisciplinary Practice was developed to highlight issues that might be encountered by each discipline and to document strategies to address these issues. Suggestions for interdisciplinary communication were also identified. The Guide was utilised as a tool to explore the roles of each discipline and localised in a number of organisations.

3.6: Develop a policy on information provision, assessment and documentation

A generic policy was developed to document how information on sexuality after stroke would be provided to clients. The policy was modified by a number of project researchers to the local needs of their service.

3.7: Repeat needs analysis

The needs analysis provided an important baseline against which improvements could be measured and described. A year after initiating their projects, only one project researcher was ready to repeat the data collection.

4. Outputs

The primary output from projects was a report documenting the needs analysis, strategies for increased compliance with Guideline 8.5 and a description or measure of outcomes.

5. Outcomes

Given the time taken to undertake the projects, the outcomes have not yet been determined by most project researchers. However, one project researcher has repeated the data collection and noted the following outcomes:

- Increased staff knowledge, confidence and comfort
- Improved SOX Audit score from 0/20 to 15/20
- Increased compliance with Guideline 8.3 from 5% to 40% of medical records audited.

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