Assessing satisfaction with a nurse-led clinical trials clinic

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Introduction

This article reports the findings of a patient satisfaction questionnaire, which was used to evaluate a newly established gastrointestinal cancer clinical trial (GICT) nurse-led clinic. The GICT nurse-led clinic was set-up to accommodate the increased clinical trial portfolio locally (Winter et al, 2011).

The successful development of a local clinical trials team has resulted in an increase in patient recruitment to randomised controlled trials (RCT) over the past 10 years (Winter et al, 2011). This ongoing recruitment and associated increase in patient follow-up, beyond standard clinical practice in some cases, increased the burden on already stretched medical clinics. In response to this increase in demand locally, and an increase in cancer incidence (DH, 2000), the development of the GICT nurse-led clinic was established to adopt the caseload of all patients treated on a GICT RCT, either with palliative or curative intent, alternating appointments between doctor and nurse-led clinics. The purpose of the nurse-led clinic was to provide a comparable service to the doctor led clinics. This followed a consultation exercise reviewing all options including further development of the medical model. The clinic was established in November 2009. Details of its establishment including roles of the practitioner, training requirements and the consultation exercise undertaken; are described in a previous article by Winter et al (2011).

Within the clinic patients are assessed by a single advanced research nurse practitioner prior to administration of multiple chemotherapy agents, and numerous antibody therapies. Assessment includes review of toxicity with grading using the Common Toxicity Criteria (National Cancer Institute, 2006), haematological and

biochemical review and physical assessment. Dose reductions or treatment delays are based on the patients' presentation and completed according to the clinical trial protocol. Prescribing of support medication is completed as part of the review, if necessary. Once patients complete active treatment and move onto surveillance, they continue to be reviewed in the GICT nurse-led clinic, which is held weekly. This involves physical assessment, review of on ongoing / delayed treatment toxicity and organisation of any necessary investigations per trial protocol. Further information about these aspects of the GICT nurse-led clinic are reported in Winter et al (2011).

All patients diagnosed with a GI tumour who had been treated in an RCT were referred to the clinic. Since this was a novel service staffed by a single Advanced Nurse Practitioner (ANP), the patient population was selected on the basis of the ANP's clinical expertise. It is expected that the numbers will increase over time as new trials are opened within the speciality.

Evaluating newly established services

Marsh and Glendenning (2005) express caution and consideration before embarking on service evaluation. Suggesting that evaluation should not be viewed as essential, but should be considered after assessment of possible findings has been considered. The need to review and evaluate any new service is derived from the following key points: efficiency of the service, or identification of any areas for development (Rossi et al, 2004); cost effectiveness of the service, including provision of further funding/ resource allocation (Ovretveit, 2009); and patient experience, including any safety issues or near misses (DH, 2009a; DH 2009b). These key points were considered when conducting the service evaluation described herein.

Using a survey tool to collect data on patient satisfaction was deemed the most appropriate method of evaluation. Surveys provide a low-cost option to obtaining limited data from larger groups of patients (Leighton et al, 2008). The data can be provided anonymously, with patient choice as to which sections are completed, without pressure or coercion (Leighton et al, 2008). It is accepted that some patients decline to complete the survey by not responding (Oppenheim, 1992).

Identification of validated tools that were fit for purpose proved challenging, since tools identified were not specific to the practice setting; therefore in-house survey tools were used as a basis to create a specific tool.

Method

Based on local Trust patient survey tools (Whittam and Buckley, unpublished; Daley, unpublished) a mixed-method satisfaction questionnaire was developed by the contributing authors to gather information about the experience of patients and their carers attending a GICT nurse-led clinic.

An IRAS application for ethical review was not required to conduct this service evaluation; however to ensure good practice, the study and tools were peer reviewed and approved by the local Trust Research and Development Unit, the Lead Cancer Manager, and Research Clinical Lead. The survey was sent out at two different time points. This ensured maximum patient coverage over the 22 months, as prognosis for some of the patients was 6-12 months. The results from the first round of surveys, and the questionnaire were reviewed by the Trust Cancer User Group before repeating the survey. The group approved the continued use of the questionnaire and were pleased with the overall results and free text comments.

Questions were developed to evaluate aspects of the service outlined in Box 1.

Box 1. Aspects of the service for evaluation

- Confidence in Advanced Nurse Practitioner
- Providing information
- Perception of a caring environment
- Running of the clinic

Both quantitative data and free-text comments were gathered and analysed using a descriptive summary.

The patient satisfaction questionnaire was developed and sent to all patients enrolled into GICT's and being seen in the nurse-led clinic between 30th November 2009 and 30th September 2011. Prior to posting the questionnaire, a check was conducted to ensure that it was only sent to patients known to be living. The questionnaires were posted by the research administration manger and cancer services administrator with a letter of invitation, and a pre-paid addressed return envelope. The letter of invitation included information about the purpose of the questionnaire, instructions on its completion and return, and a statement about protection of anonymity and confidentiality. The results were collected on a simple spreadsheet detailing each question and the subsequent answers in the corresponding columns. The analysis was undertaken by Helen Winter (HW) and Verna Lavender (VL) using the statements detailed in box 1.

42 patients were issued with a patient satisfaction questionnaire: 35 (83%) responded. The survey included fixed-questions on 4 key aspects of the clinic: confidence in the ANP; provision of information; perception of a caring environment; and organizational running of the clinic. Empty boxes for free-text comments were also provided. Respondents indicated satisfaction with the clinic being run by a nurse, the provision of information, the provision of a caring environment and information about clinic logistics. 4 respondents indicated that they would have preferred to have been seen by a doctor.

Results

35 (83 %, n = 42 patients) respondents returned completed questionnaires. Demographic data indicate that 34 questionnaires were completed by the patient. 32

(76%) patients issued questionnaires were male and 10 (24%) were female. 74% (26) of respondents were male, 20% (7) were female, which is representative of the gender of the patient group. 6% (2) did not provide information about their gender. Of the 42 patients issued questionnaires 11 were <59 years (26%), 18 were 60-69 years (43%), and 13 were >70 years (31%). 25% of respondents were <59 years, 43% were 60–69 years, and 29% were >70 years. Respondents were asked to provide their age range and not actual age. A summary of responses are shown in Table 1.

Aspect of Service	*Question*	*Yes (%)*	*No (%)*	*Can't remember (%)*	*Not applicable (%)*	*Total*
Running of the Clinic	1. Were you informed that you might be reviewed in the clinical trials nurse-led clinic?	32 (91%)	0	3 (9%)	NA	100
Perception of a Caring Environment	2. Did the trials nurse always introduce herself?	34 (97%)	1 (3%)	0	NA	100
Proving Information	3. Did you receive information about the treatments you would be receiving?	34 (97%)	1 (3%)	0	NA	100
Providing Information	4. Unless you declined, did you receive copies of your clinic letters?	34 (97%)	0	1 (3%)	NA	100
Providing Information	5. Did you find these clinic letters helpful and informative?	34 (97%)	0	1 (3%)	NA	100
Not included results	**6. Did you feel anxious about the consultation?**	**35 (100%)**	0	0	NA	100
Running of the Clinic	**7. Did the clinic run late?**	**20 (57%)**	13 (37%)	2 (6%)	NA	100
Running of the Clinic	8. If the clinic was running late, were you informed?	17 (49%)	4 (11%)	2 (6%)	1 (3%)*	* 1left blank
		Yes, always (%)	*Yes, sometimes (%)*	*No, never (%)*	*Can't remember (%)*	*Total*
Providing Information	9. I was involved in the decisions that were made about my treatment.	30 (86%)	2 (6%)	0	2 (6%)	*1 left blank
Providing Information	10. The clinic nurse provided me with enough information about the side effects of the treatment.	33 (94%)	1 (3%)	0	0	* 1 left blank
Providing Information	11. The clinic nurse was able to assess my symptoms and provide the treatment I needed.	28 (80%)	5 (14%)	1 (3%)	0	* 1 left blank
Confidence in the ANP	12. I was confident in the decisions made by the clinic nurse.	33 (94%)	1 (3%)	0	0	* 1 left blank
Perception of a Caring Environment	13. My views and feelings were considered and I was given a chance to discuss these.	33 (94%)	0	0	1 (3%)	* 1 left blank
Perception of a Caring Environment	14. I received a warm welcome from the nurse.	32 (91%)	2 (6%)	0	0	* 1 left blank
Providing Information	15. I understood what the nurse was telling me.	30 (86%)	4 (11%)	0	0	* 1 left blank
Providing Information	16. The nurse explained the risks and benefits of any proposed treatments	34 (97%)	0	0	0	* 1 left blank
Providing Information	17. The nurse explained how to take any medicines prescribed.	33 (94%)	1 (3%)	0	0	* 1 left blank
Providing Information	18. I understood how to take the medication prescribed by the clinic nurse.	33 (94%)	1 (3%)	0	0	* 1 left blank
		Strongly agree (%)	*Agree (%)*	*Disagree (%)*	*Strongly disagree (%)*	*Total*
Confidence in the ANP	19. It was obvious that the nurse was able to discuss my case with my consultant.	21 (60%)	13 (37%)	0	0	* 1 left blank
Perception of a Caring Environment	20. I felt my privacy and dignity were respected at all times.	26 (74%)	8 (23%)	0	0	* 1 left blank
Perception of a Caring Environment	21. I was made to feel at ease at all times.	23 (66%)	10 (29%)	1 (3%)	0	* 1 left blank
Perception of a Caring Environment	22. There was sensitivity towards any special needs I have.	22 (63%)	12 (34%)	0	0	* 1 left blank
Providing Information	23. I was helped with any symptoms that I was experiencing.	22 (63%)	12 (34%)	0	0	* 1 left blank
Confidence in the ANP	24. I was confident in the nurse that saw me.	25 (71%)	9 (26%)	0	0	* 1 left blank
Confidence in the ANP	25. I was happy to be reviewed in the nurse-led trials clinic.	23 (66%)	10 (29%)	1 (3%)	0	* 1 left blank
Confidence in the ANP	**26. I would have preferred to be seen by a doctor.**	**2 (6%)**	**2 (6%)**	21 (60%)	2 (6%)	*8 left blank
Confidence in the ANP	27. I felt I could contact the clinic nurse or other research nurse at any time.	22 (63%)	11 (31%)	0	0	* 2 left blank
Providing Information	28. I was provided with either verbal or written support each time I was seen in the nurse clinic.	21 (60%)	13 (37%)	0	0	* 1 left blank
Providing Information	**29. I would have liked more information on how to take my medication.**	**2 (6%)**	**1 (3%)**	21 (60%)	7 (20%)	*4 left blank
Confidence in the ANP	30. I was able to ask questions.	25 (71%)	9 (26%)	0	0	* 1 left blank
		Excellent (%)	*Good (%)*	*Adequate (%)*	*Poor (%)*	*Total*
Confidence in the ANP	31. If you were able to ask questions, how would you rate the response you received?	28 (80%)	5 (14%)	1 (3%)	0	* 1 left blank
		On time (%)	*Up to 30 minutes (%)*	*Up to 1 hour (%)*	*More than 1 hour (%)*	*Total*
Perception of a Caring Environment	32. How long did you have to wait to be seen?	11 (32%)	18 (51%)	5 (14%)	**1 (3%)**	

Table 1. Responses to service evaluation questionnaire

Using categories shown in Box 1 responses were group and analysed as either positive or negative responses. Positive responses are shown in standard font, negative responses are shown in bold font. Findings under each category are reported below.

Confidence in the advanced nurse practitioner

259/280 responses (92%) selected, indicate that respondents were confident in being managed by a nurse; this finding is also reflected in the free-text comments. However, 4 (11%) of respondents would have preferred to have their appointment with a doctor.

Providing information

This category encompasses information about the consultation, treatment, side effects, symptom management, and decision-making about ongoing clinical trial participation. 433/455 responses (95%) indicated respondent satisfaction with information provided about their treatment, management of side effects and symptoms and being involved in the decision-making process. 3 (9%) of respondents would like additional information of how to take medication prescribed.

Perception of a caring environment

35 (100%) of respondents selected that they felt anxious about their consultation, but given the style of questioning and context of the questionnaire, it was difficult to determine if they were anxious about attending a nurse-led clinic, or were anxious from other pre-occupations related to their disease and treatment. 202/210 responses (96%) indicate that respondents were positive the service was provided in a caring environment.

Running of the clinic

Respondents felt informed about the clinic; although 1 patient responded that “the nurse did not introduce them self”. 20 (57%) of respondents reported that the clinic was running late; in such instances 4 (11%) of respondents indicated that they were not informed of the delay.

Anxiety has not been included in a specific aspect of the service evaluation but has been acknowledged as significant to all patients reviewed and will therefore be addressed as a separate issue.

Free-text comments

The majority of free text comments made positive value statements including the words “excellent” and “superb”. Negative comments were about delayed appointments and long waiting time in clinics. One respondent commented about other departments within cancer services. Examples of representative free text comments include: “The treatment and care I received was excellent”. “No criticism whatsoever from any aspect or person involved from beginning to end of my treatment”. “Throughout my treatment I was treated superbly with all the professional treatment anyone could ask for”. “Re the majority of clinics - I do feel that more attention should be paid to seeing all patients promptly”. “I would have liked my time with the nurse half hour before my treatment so I went for my chemo on time, so I did not then have to wait for that”. “I am very happy as you can see from my responses”.

Discussion and conclusions

Overall, the GICT clinical trial nurse-led clinic is well-evaluated. Respondents indicate satisfaction with areas of the service related to being run by a nurse, the provision of information, the provision of a caring environment, and being provided information about clinic logistics. The service could be improved by providing patients with a choice of whether they have an appointment with a nurse or doctor. This will ensure patient choice about who provides their care is considered.

A review of the allocated clinic times, with adjustments to the length of time is recommended, as a high percent of patients reported delays. Such delays are not acceptable in any settings, but the impact for patients on quality of life and those with poor prognosis needs careful consideration.

A greater degree of explanation for the taking of medication will be incorporated into each assessment and review. Any changes to medication will be documented in the clinical dictation sent to the general practitioner and copied to the patient.

It is also recommended that future survey tools remove the ‘can’t remember’ response option, as meaningful data cannot be drawn from this response.

Anxiety was significant for all patients. It is not know what aspects of the clinic caused anxiety and therefore this needs to be addressed individually for each patient reviewed. In order to achieve this the ANP will, as appropriate, conduct an holistic assessment (National Cancer Action Team, 2011) and address each patients needs individually.

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