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A single educational seminar increases confidence and decreases dropout from Active Surveillance 5 years following diagnosis.

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Abstract:

Background: Researchers remain divided on the major causes of active surveillance (AS) drop-out; with rates as up to 38% in men with no evidence of disease progression.

Objective: To develop and evaluate the value of an educational intervention on adherence to AS in men with low-intermediate risk prostate cancer (PC).

Design, Setting and Participants: We carried out focus group discussions with men who had remained on and dropped out of AS to inform an intervention to increase adherence to AS. 255 consecutive men who had selected AS were recruited to either standard care (written information and access to a nurse specialist) or standard care and intervention.

Intervention: An educational seminar was designed by patients and clinicians including information on imaging, biopsy techniques, understanding pathology, large AS cohorts - mortality and morbidity risk and diet and lifestyle advice.

Outcome Measurements and Statistical Analysis: Proportions dropping out of AS for reasons other than disease progression were assessed, at 1 and 5 years from AS selection using multivariate logistic regression.

Results and Limitation: Common themes were found to influence men's decision making on AS: (1) Clinical consistency (2) Information (3) Lifestyle advice.

The addition of an educational seminar led to significantly fewer men dropping out of AS at 1 and 5 years, from 25% and 42% respectively in the standard care group to 11% and 22% (p=0.001) in the standard care plus seminar group.18 men in the intervention group failed to attend the seminar.

Conclusion: The AS drop-out rate was halved following a single educational seminar delivered to groups of men with intermediate or low risk PC, even at 5 years.

Patient Summary: Men on AS feel more supported when being provided with an educational seminar within three months of treatment choice; halving the number of men dropping-out of AS, even at 5 years.

1.0 Introduction

European guidelines suggest a large proportion of men with localized, low-risk prostate cancer (LRPC) do not require immediate treatment, but can be monitored – an approach known as active surveillance (AS) [1]. However, international variation in determinants for safe AS inclusion and follow-up [2] continue to contribute to high AS drop-out rates (up to 38%) in men with no evidence of disease progression [3].

Researchers remain divided on the major causes of AS drop-out. A recent systematic review of AS choice and adherence literature [4] reported six domains driving unnecessary AS drop-out: (1) patient characteristics; (2) tumour characteristics; (3) family and social support ; (4) provider; (5) healthcare organisation; and (6) health policy.

However, informational interventions aimed at men on AS have widely reported a favourable impact on AS adherence. Oliffe [5] found that self-management strategies helped men cope with some of the long-term uncertainty of AS, whilst ‘The Prostate Cancer Lifestyle Trial’ based on lifestyle modifications, including exercise and attention to stress management, demonstrated an improved treatment-free survival on AS [6]. Goh [7] found that men who perceived that they were receiving useful and consistent information were more satisfied with AS and therefore more likely to continue on AS whilst the UK based ProtecT Trial [8] found merit in consistency of personnel to support and inform patients. Interventions relating to peer support have also demonstrated a significant improvement in the quality of life of men with any stage of PC [8, 9].

Here we describe the development and evaluation of an intervention using a standardised information and support delivery technique which aims to increase AS adherence based on previous research efforts and local focus groups.

2.0 Patients and methods

This applied research project consisted of two parts: (1) Focus groups (FGs) to understand motivation and needs of men on AS and to explore practicalities of an intervention to support AS adherence; (2) Pilot intervention study to assess effect.

2.1 Focus groups

Permission was obtained from the local Urology audit committee to identify potential participants through electronic records (No:U13887). In December 2009 and April 2010, two FGs were facilitated by the Clinical Nurse Specialist (CNS) team. The first consisted of eight men who were currently on AS and the second of seven men who had dropped out of AS without evidence of progression. A semi-structured question guide was developed to provide structure for each FG (Appendix 1), based on a review of the available literature at this time [10].

We employed thematic analysis, an inductive process designed to identify and examine emerging themes from conceptual data [11]. Thematic saturation in qualitative data has been reported at 15 (interview studies) [12] and therefore two FGs were scheduled. Purposive homogenous sampling was employed to provide conceptual significance to the question of adherence [13].

2.2 Developing the Intervention (Educational Seminar)

The intervention was developed in line with recommendations from the FGs. A power-point presentation was co-authored by patients, nurses, and doctors with final ratification by the AS reference group (4 partners of, and 10 men currently on or previously on AS).

The proposed 1.5 hour seminar included information on: imaging, biopsy techniques, understanding pathology, large AS cohorts - mortality and morbidity risk and diet and lifestyle advice. Optimal seminar delivery was defined as a team approach: urologist and CNS. Time was scheduled at the end of the seminar for questions and peer group discussion.

2.3 Recruitment

We employed a method of consecutive sampling [14] appropriate to a process of service improvement where a standard of care is evaluated both prior and after intervention. The inclusion criteria was men diagnosed with low-intermediate risk PC (as defined by the D’Amico classification system [15] appendix 1), suitable for AS based on information from Magnetic Resonance Imaging (MRI) and transrectal prostate biopsy with confirmatory transperineal prostate biopsy. The AS progression criteria was, >G3+4 (transperineal biopsy approach - minimum 24 cores) or where the maximum contiguous cancer length was ≥6mm, >MRI - T2b, ≥30% of cores positive. Follow-up was carried out according to NICE guidelines (Appendix 2).

Between January 2011 and June 2011, 135 men were recruited (Group A), and offered standard care (NICE [16]: introduction to a CNS and written information on AS (PCUK [17]). A second consecutive group recruited between July 2011 and December 2011 (Group B) included 120 men who were offered standard care and participation in the educational seminar.

This study compared AS drop-out rates at 1 and 5 years post diagnosis. Patient and clinical characteristics at diagnosis, and outcomes were compared between both groups using descriptive statistics. Multivariate logistic regression, adjusting for age, grade, diagnostic PSA, digital rectal examination and clinical stage examined whether differences in drop-out rates were independent of patient characteristics.

3.0 Results

3.1 Qualitative analysis

3.1.1 Designing the intervention: FGs

The themes emerging from the two FGs were (1) consistency in clinical team, administration and follow-up protocol, (2) consistent information re: PC and AS, (3) diet and lifestyle advice.

(1) Clinical consistency (Panels 1 & 2)

In both FGs, men described importance of a consistent approach to follow-up as well as familiarity with the clinical team.

Men still on AS found reassurance: "*my CNS always sees me for my PSA review, I have a great relationship with her, I could ask her anything*".

Men in the group that had dropped out of AS described their experience as stressful: "*nobody could give me any guarantees abot AS follow-up, every guideline seemed to be different. It made me very nervous*". They also described inconsistencies in the clinical team as: "*very difficult"*.

(2) Consistent information (panels 3 & 4)

The two FGs differed in their response to the information given during AS. Those who had remained on AS felt that the amount of information given was adequate: "*I was given some information leaflets by my CNS. I thought they were very good*". The men who had dropped out of AS described the information as inconsistent: "*every time I saw a new doctor or nurse I would question them about PC and AS. Sometimes the answers were the same, other times they sounded like they didn't know what they were talking about*".

(3) Diet and lifestyle advice (panels 5 & 6)

Men remaining on AS described self-help as a major contributor to their quality of life. "*I found lots of information on the internet about diet and* *exercise. I changed my diet and began to go to the gym. I think everyone who has cancer should be aware. I've never felt better*".

Men who had opted out of AS suggested that: "*there really wasn't any information on how I might help myself on AS*" and "*I don't think the nurses or doctors believed that diet, exercise or complimentary treatments would help on AS. I might have stayed on AS if I'd had the opportunity to discuss this*".

3.1.2 Developing the intervention

The FGs discussed the medium through which the information and support should be given: website, bespoke written information, webinar and peer-group seminar. Men who had dropped out of AS described their experience of websites and on-line forums as "*cold*". The men who had remained on AS, felt that websites gave no opportunity for feedback and that the forums, although interactive in some cases, were "*extreme and unpoliced*". There was universal agreement that the content of the intervention should be empowering, with an emphasis on self-care. Thirteen of fifteen participants agreed that a peer group one-off educational seminar would suit the needs of the majority, with an option to re-attend when/if required. The seminar was suggested to be held within three months of choosing AS to mirror the early support and information that men undergoing radical treatment received.

It was also suggested that the content of the seminar had to be similar to our program of seminars offered to men undergoing prostatectomy and radiotherapy [18]. Five topics were agreed on: Imaging, biopsy techniques, pathology, mortality and morbidity risk in AS and dietary and lifestyle advice.

3.2 **Quantitative analysis**

3.2.1 Patient demographics

273 men were recruited to the study. 18 men in the intervention group failed to attend the seminar and were therefore omitted from the final analysis. This left 255 men, 135 in group A and 120 in group B (Figure 1).

No statistically significant differences were found between the two groups for age, PSA and DRE clinical stage at study entry (Table 1). A statistically significant difference was, however, found in relation to Gleason grade group (GGG): 42 men (31%) in group A compared to 111 (93%) in group B with GGG1. 93 men (69%) in group A and 9 men (7%) in group B were diagnosed with GGG2. This was felt to be most likely associated with an increase in confidence for local AS monitoring practice in the intermediate PC risk group [19].

3.2.2 Adherence to AS

No men demonstrated clinical disease progression in the first year. However, 25% of group A compared to 11% in group B did drop out of AS (Table 2) (p=0.003).

By year 5, patients in group B remained less likely to drop out of AS. Drop-out without evidence of progression was 21.7% in group B compared to 41.5% in group A (p<0.001) (Table 2). Due to the difference in clinical characteristics between the two groups, at 5 years following diagnosis the AS drop-out rate due to cancer progression was higher in group B than in group A, 21.7% versus 12.6% [20, 21].

Drop-out rates remained significantly lower among seminar participants, after adjustment for baseline clinical characteristics, including GGG, at both 1 year (OR = 0.21, 95% CI 0.09-0.49) and 5 years (OR=0.26, 95% CI 0.12-0.56) (Table 3). Identical results were found when restricting the analysis to GGG1 with an odds ratio of 0.25 (0.11-0.53) for drop out in patients without evidence of disease progression at 5 years.

4.0 Discussion

This is the first mixed methods study to develop and assess impact of an educational/supportive intervention on AS adherence over a 5 year period. Our findings demonstrated effectiveness of a structured, interactive, educational seminar in increasing adherence to AS for men with low-intermediate risk PC.

The needs of men requiring radical treatments for PC have been examined previously and have helped to define and develop the role of the CNS in supporting patients [22]. However, less is known about the resources and requirements of men selecting AS or engaging in long-term AS. A recent qualitative study suggested six requirements of men on AS [23]: (1) general information on PC and how to interpret results; (2) specific information on AS investigations, follow-up, mortality risk; (3) complementary options regarding diet, lifestyle, exercise; (4) variety of resources; (5) social support and interaction and (6) verification of integrity of information. These requirements were reflected in our own FGs. Men who had opted out of AS felt particularly strong about this.

4.1. The clinical team

The patient relationship with the clinical team is an important variable in adherence to healthcare, but it is difficult to assess the nature of this interaction and to measure its components. Poor communication is traditionally measured in terms of a patients' inability to recall clinician instructions, with patients failing to recall between one-third and one-half of statements given to them [24]. One FG participant suggested;

Participant 9 (69y)…."The doctor didn't even let me sit down, he greeted me at the door and said your PSA is fine, see you next year. I had questions, I wasn't encouraged to ask them"….."after leaving the clinic I couldn't even remember what my PSA level was, I had to call the nurse later that same day. 'I was told all I needed to know was that I didn't need to worry myself – that was it, end of conversation".

Initial selection of AS is strongly associated with multi-disciplinary care [25]. However, whilst multidisciplinary clinics are recognised as advantages in optimizing AS choice, our FG feedback suggests that variability in personnel managing AS leads to specific concerns regarding consistency. This was demonstrated through commentaries from several participants (Panel 2).

However, the combination of CNS and doctor has been found to benefit men with PC. Tarrant [26] and Ream [27] both found that men who had accessed a CNS reported a more positive experience of their cancer management. Our FGs confirmed that a combination of medical and nursing staff was optimal in giving information and supporting men on AS (Panel 1).

4.2 Detailed and consistent information

Information has a variety of benefits for cancer patients, particularly anxiety reduction, improved ability to cope with treatment and better self-care. Information can help empower patients. Recognition of the role that support and information plays in effective cancer care is not new. In 2002, NICE commissioned a report focusing on improving outcomes in urological cancers [28]. It recognised that in PC in particular, the appropriate management strategy may depend on an individual's values and attitudes, but should include: Information about basic anatomy and pathology, PC and the individual variation in its impact and rate of progression, treatment options, probability of survival, symptom reduction, risks and potential short- and long-term effects. Our FGs demonstrated frustration in this respect, describing a lack of clarity about that appeared to extend to the medical and nursing team (Panel 4).

O'Callaghan [29], Oliffe [5] and Davison [30] found that patients on AS became particularly stressed where information given by the clinical team was contradictory or inconsistent. Our FG participants also agreed that there was inconsistency, describing a lack of objective, robust information and poor descriptors of disease risk and AS (Panel 4).

The FGs discussed both delivery method and type of information and support required. All agreed with a 2010 FG study which reported that information on the internet was contradictory, limited and difficult to find [31] and therefore a dedicated informational source was required.

Many of the men who had dropped out of AS and had later chose to undergo radical treatment also remarked on the inconsistent approach to information and support services between men offered AS and those undergoing radical treatment.

Our group previously reported a significant increase in patient satisfaction when offered access to a peer-group educational seminar on radical prostatectomy [18]. Galbraith *et al*. [32] described how this can provide a sense of meaning in men's experience of PC. FG participants also suggested that mimicking the information and support given to patients in other treatment groups may influence behaviour of the health professional team by endorsing AS as a valid treatment option [4].

4.3 Diet and lifestyle advice

A 2015 systematic review of supportive care in PC highlighted self-care in nine papers [33]. Authors discussed empowerment and sense of control that comes from self-care through lifestyle changes. Nanton found that ‘taking an active part in their own health management men were taking control of their illness'[34]. This was also described by Oliffe [5] and O'Shaughnessy [35] who demonstrated the merits of using strategies similar to men at other stages of disease combining 'living a normal life' with 'doing something extra', e.g. dietary or lifestyle changes. This appeared to increase both acceptability and adherence to AS and was also described by our FG participants (Panel 5).

5.0 Study limitations

Our assignment of men to intervention and standard care was not randomised, but occurred over consecutive time periods as part of an audit/service improvement project where the intervention was the 'new' standard of care. It is not possible to exclude the influence of clinical practice which that may have occurred over this time period e.g initial undersampling due to biopsy practitioner experience or learning curve of MRI imaging team. This may contribute in part to the higher proportion of men progressing in the intervention group despite a significantly higher number of men in GGG1 at diagnosis.

Further, the two comparison groups differed in GGG, which may have influenced adherence. However, the differences remained statistically significant, even after adjustment for clinical characteristics such as GGG at diagnosis. We were however unable to adjust for other recognised confounding factors such as marital status, ethnicity and education level.

18 patients were excluded from the study as they failed to attend the seminar intervention. Follow-up with this patient group may have added value in reducing future non-attendances.

6.0 Conclusion

Findings from this study demonstrate that men on AS desire consistency in contact with staff, appointments and information. Subsequent evaluation of this intervention demonstrates that a peer-group educational seminar, delivered by the clinical team in the initial months after starting AS, reduces the likelihood of dropping out of AS by 50%. With the trend towards AS in LRPC increasing, interventions like this could help assuage the upward drift in healthcare costs worldwide.

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Table 1: Patient characteristics and adherence of study participants in both arms of the non-randomised intervention study.

	Standard Care (Group A)	**Educational Seminar (Group B)**	**p value**
	n=135	n=120	
Characteristics at AS entry			
Mean Age (SD)	62.4 (6.8)	63.3 (7.4)	0.34
Mean PSA (SD)	9.2 (7.0)	8.6 (5.3)	0.42
	n (%)	n (%)	
Grade			
3+3	42 (31.1)	111 (92.5)	0.001
3+4	93 (68.9)	9 (7.5)	
DRE assessment			
Benign	47 (34.8)	46 (38.3)	0.56
T2	77 (57.0)	68 (56.7)	
T3	11 (8.2)	6 (5.0)	

Table 2: Active surveillance outcomes based on intervention group at 1 and 5 years.

Program outcomes	**Standard Care (Group A)**	**Educational Seminar (Group B)**	**p-value**
At 1 year:			
Remained in AS program	101 (74.8)	107 (89.2)	
Dropped out due to disease progression	0	0	
Dropped out with no disease progression	34 (25.2)	13 (11.2)	0.003
At 5 years:			
Remained in AS program	62 (45.9)	68 (56.7)	
Dropped out due to disease progression	17 (12.6)	26 (21.7)	0.053
Dropped out with no disease progression	56 (41.5)	26 (21.7)	<0.001

Table 3. Multivariate logistic regression for odds of dropout for reasons other than disease progression. All models were adjusted for age, grade, diagnostic PSA, digital rectal examination and clinical stage.

Patient characteristics (at entry into AS)	**At 1 year** n=253	**By 5 years** (whole cohort) n=253	**By 5 years** (excl. men with disease progression) n= 210	**By 5 years** (excl. men with disease progression and GGG2) n=125
	OR (95% CI)	**OR (95% CI)**	**OR (95% CI)**	**OR (95% CI)**
Educational seminar				
no	1.00	1.00	1.00	
yes	0.21 (0.09-0.49)	0.25 (0.12-0.51)	0.26 (0.12-0.56)	0.25 (0.11-0.57)
Age (continuous)	1.03 (0.98-1.09)	0.94 (0.91-0.98)	0.93 (0.90-0.98)	0.95 (0.90-1.00)
PSA (continuous)	0.94 (0.88- 1.01)	0.96 (0.52-1.01)	0.98 (0.93-1.04)	0.97 (0.89-1.06)
Gleason Grade Group				
GGG1	1.00	1.00	1.00	n/a
GGG2	0.44 (0.20-0.97)	0.49 (0.23-1.00)	0.48 (0.22-1.02)	n/a
DRE				
Benign	1.0	1.00	1.00	
T2	0.88 (0.43-1.79)	0.98 (0.54-1.77)	0.93 (0.50-1.72)	0.75 (0.33-1.71)
T3	1.42 (0.41-4.91)	1.69 (0.54-5.32)	3.88 (0.96-15.7)	3.52 (0.51-24.0)