RESEARCH COMMUNICATION

Empirical Comparisons of Patient Delay and Help Seeking Models for Breast Cancer: Fitness of Models for Use and Generalisation

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Abstract

Background: Health behaviour models are continuously being developed to investigate patient delay and help seeking behaviour for breast cancer. Their fitness for generalisation to another setting has not been examined and little is known of their appropriateness for use. Methods: The models' building blocks (theories, concepts, constructs and variables) and settings were systematically examined and compared. Results: Six models of patient delay and help seeking for breast cancer were developed in a period of seven years (2003-2010). Theories of individual and interpersonal health behaviour, and various combinations of concepts and constructs were used to build these models. There is a lack of consensus in the terminology used to define constructs and variables. Constructs and variables together explained some of the variance of patient delay and help seeking. Conclusion: Existing patient delay and help seeking models for breast cancer were tested and yielded some degree of confirmation of their ability in explaining delayed presentation and help seeking behaviour. More models are likely to be developed in the future to account for factors currently missing in the existing models. To ease this process, there is a need for greater consensus and a shared conceptual language, as well as to advance knowledge and research in this field.

Asian Pacific J Cancer Prev, **12**, 1589-1595

Introduction

Patient delay for medical attention for cancer symptoms is associated with advanced tumour stage at diagnosis and poor survival rate (Richards et al., 1999). Research attempting to understand the reasons patients presented late is relatively new; the first study was published in the 1990s (Zervas et al., 1993). Most studies were examining survival and the associations between socio-economic and demographic variables with late presentation (Richards et al., 2009). Understanding late/delayed presentation or patient delay is crucial to improve early diagnosis and reduce the mortality of the disease.

Increased attention given to this public health issue in both the western (Richards et al., 2009) and non-western worlds (APOCP, 2010) also means that more models will be prescribed in the near future. Given the choices, what model should one use and which model is most accurate in explaining patient delay, predicting help seeking for medical attention or motivating behavioural change?, remained important questions that are often asked by students, researchers and practitioners.

Models of patient delay and help seeking for breast cancer are continuously being introduced but their reasons are not always clear. Is it because existing models are inadequate to explain or predict the phenomena in question and/or promote behavioural change? These models have not been analysed or synthesised and thus, little is known of the accuracy of the models; what are the constructs (and variables) that are more influential than others; or which behaviour or situations are better understood in one model than others.

Noar and Zimmerman (2005) suggested three alternatives to consider when faced with a decision to choose a theory or model to understand health behaviour. These are: proliferation and testing of existing theories or models; theoretical integration, which is, selecting the most supportive constructs from different theories and combining them into a single theory or model; and theoretical comparison, which is, comparing and examining for consensus in the concepts and constructs used in the theories. The authors emphasised the importance of theoretical comparison as a way forward to cumulate knowledge and advance our understanding of health behaviour and argued for more research in this area. Similar view is shared by others (Weinstein, 1993; Zimmerman & Verberg, 1994; Nigg et al., 2002).

Theories and models of health behaviour are mostly

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developed and tested in the western world. If they are to be transferred or generalised to another setting, evidence is needed not only of their accuracy in representing a phenomenon in a different setting but also the appropriateness and relevance to a particular culture and context. In addition to comparing theories and models for consensus, theory or model per se should be examined to provide answers to: Is generalisation to another setting possible? What is the fit of a model in another culture and context? How effective and comprehensive is a model in capturing the problem or explain the phenomenon in another setting?

The present article aims to empirically compare the patient delay and help-seeking models for breast cancer in an attempt to find answers to the questions raised above. In order to assess the models' external validity, in term of the appropriateness of generalisation to another setting and population for which the models were developed will also be examined.

A single, unified theory is not able to explain the complexity of health behaviour; models therefore are used. Model draws on a number of theories to help understand a specific problem or phenomenon in a particular setting or context. Theories are made of concepts; concepts are the major components and building blocks or primary elements (Glanz et al., 2008). When concepts are developed or adopted for use in a particular theory, they are called constructs (Kerlinger, 1986). Variables are the empirical counterparts or operational forms or measures of constructs. Figure 1 depicts the building blocks of a model.

Materials and Methods

A systematic search was performed on the databases of MEDLINE(Ovid), PsycINFO(Ovid), Health Management Information Consortium (HMIC), Science, Social Science and Conference proceedings Citation Indexes (Web of Science, Thomas Reuters) and Global Health. The search strategy was based on the concepts of 'Patient Delay, Early/Late/Delayed Presentation/Diagnosis, Care/Help/Health seeking, and Breast Cancer (MeSH terms applied)' and a limit to the year of publication from 1970 to most current was adopted.

The individual building blocks of the patient delay and help seeking models for breast cancer were systematically compared for fundamental differences and commonalities between models. The external validity of the models was examining using the models' results, target populations and contexts. The data extracted from the models will be tabularised for comparison and analysis.

Results

The search yielded 153 articles. Of these, seven articles were relevant and were reporting models or frameworks proposed to investigate why women did not present themselves to the doctors upon symptom(s) discovery. Andersen and colleagues proposed the first model in 1995, the Total Patient Delay model, to delineate help seeking for cancer symptom(s) in five consecutive stages, namely appraisal, illness, behavioural, scheduling and treatment delays (Anderson et al., 1995). Of these, the appraisal delay stage was found to explain 60% variance of the model.

The Total Patient Delay model however does not elucidate sufficiently the behaviour, decision making process and influencing factors within the stages. To address this limitation, six models were developed to determine the factors influencing help seeking behaviour upon the discovery of breast cancer symptom(s) between 2003 and 2010. These are, the Judgement to delay (Facione et al., 2002), Passive detection and help seeking model (de Nooijer et al., 2003), Understand delayed presentation (Bish et al., 2005), Care-seeking (Reifenstein, 2007), Prolonged delay models (Rauscher et al., 2010), and Health seeking behaviour and influencing factors framework was published most recently on line at the end of 2010 (O'Mahony et al., 2010). All the six models were developed in just a decade and all focused their investigations at the appraisal delay stage of Andersen and colleague's model. The building blocks of these models, and their settings were extracted and tabularised.

A comparison of the building blocks and settings across the models revealed differences in the choice of health behaviour theories, the constructs, and variables used; a lack of consensus in the terminology across the models; and variation in the settings and populations targeted. The tested models yielded some evidence confirming the effectiveness of the models in explaining patient delay and help seeking for breast cancer to some extent.

Use of theories

The concepts in these models were drawn from the individual and interpersonal health behaviour theories (Table 1). For detailed descriptions of these health behaviour theories, please read Glanz et al. (2008). All, except the Passive detection model (Facione et al., 2002), integrated concepts of both the models of individual and interpersonal health behaviour. For individual health behaviour models, the health beliefs model and theory of planned behaviour were applied. For interpersonal health behaviour models, concepts from the social support theory, social cognitive theory (in particular the self-regulation theory) and theory of stress and coping were adopted.

Although most of the models applied both the individual and interpersonal health behaviour models, they did not share similar conceptual combination. Two models included an 'environment determinants' concept, i.e. facilitating conditions (healthcare access and utilisation) (Rauscher et al., 2007; O'Mahony et al., 2010) while 4 included the 'social supports' concept (Facione et al., 2002; Bish et al., 2005; Reifenstein., 2007; O'Mahony et al., 2010).

Aims of models

The 6 models were developed for different purposes namely, to explain patient delay in breast cancer patients, determine likelihood to delay and intention to help seeking amongst healthy individuals. The aim of a model will determine the concepts adopted and subsequently, the constructs and variables used. For example, models that

Table 1. Theories, Concepts and Constructs Representing Patient Delay and Help-seeking Breast Cancer Models

Theories	Concepts	Judgement to delay [12]	Passive delay[13	Understanding delay[14]	Care seeking [15]	Prolonged delay [16]	Health seeking [17]
Health behaviour theories that focus on individuals	Attitudinal beliefs	Belief and knowledge, problem definition	Attitudes to paying attention, knowledge	Knowledge and symptom appraisal	Clinical variables	Knowledge determined by family history and past benign problem	Knowledge and beliefs
	Self-efficacy beliefs/beliefs about control over behaviour	Habit to health service usage	Self efficacy, behaviour	Confidence in self-detecting symptom	-	-	Health service habits
	Normative and norm-related beliefs and activities	Affective responses; health services system variables	Moral obligations, social norms, modelling				
	-	Social norms, facilitating conditions	-	-			
	Risk-related beliefs and emotional responses	Risk attribution	Anticipated regret	-	Utility	-	Operated in the Knowledge and Beliefs construct
	Intention/ commitment/ planning	-	Behaviour				
	Intention to seek help	Planful problem solving	-	-			
Models of interpersonal health behaviour	Social support	Relationships constraints	-	Disclosure of symptoms	Social support	-	Social factors
	Stress, coping	-	-	-	Fear, denial, coping	-	Psycho-logical factors
	Self regulation through self-monitoring, goal-setting, feedback, self-reward, self-instruction, enlistment of social support	-	-	Attitudes to help seeking – variables measured by Self-regulation theory	-	-	-
	Environ-mental determinants of behaviour (health policies, facilitation with provision of new structures/ resources/ training)	-	-	-	-	Health insurance -Healthcare access and utilitsation	Health service utilisation

are intended to measure intention to seek help included the constructs of self-efficacy beliefs, risk-related beliefs and intention/commitment/planning. Many of the existing models had both the explanatory and behavioural aspects.

The Understanding Patient Delay model (Bish et al., 2005) was also intended as a guide for developing interventions to change behaviour and promote awareness of the disease.

Use of terminology

Many of these models contain similar or identical constructs although different terms/names were used to

Table 2. Patient Delay and Help-seeking Models for Breast Cancer: Constructs and Variables

Model	Constructs	Variables
Total patient delay model [11]	Appraisal delay	Detects unexplained signals/symptoms, infers illness (descriptions of symptoms)
	Illness Delay	Decides to seek medical attention
	Behavioural Delay	Acts on decision by making an appointment
	Scheduling delay	First receives medical attention
	Treatment delay	Begins treatment for illness
Judgement to delay model [12]	Problem definition: symptom appraisal	Symptom knowledge, risk attribution, affective response
	Relationships constraints	Role obligations, cultural expectancies, family dynamics
	Affective responses	To the symptom and the expected treatment
	Health services system variables	Perceived access, economic constraints, expectations of prejudice, provider issues, immigration issues
	Health services usage	Health services habits, cancer screening habits, self care habits
	Beliefs and knowledge	Of curability potential, of the consequences of delay, in the influence of spirituality, in the efficacy of alternative therapies
Passive detection and help seeking model [13]	Attitudes	towards paying attention to cancer symptoms (pros and cons)
	Moral obligations	to yourself and family to pay attention
	Anticipated regret	Of not carrying out action
	Social norm	partner's value about care seeking
	Modelling	after people around you)
	Self-efficacy ability	Ability to pay attention to cancer symptoms
	Behaviour	How often do you pay attention to each symptom? The period of time elapsed before consulting doctor.
	Knowledge	Knowledge of symptoms
Model to understand PD [14]	Symptom appraisal	Variables investigated in the self regulation theory
	Attitudes to help seeking	Variables investigated in the self regulation theory
	Disclosure of symptoms	Variables investigated in the self regulation theory
	Intentions to seek help	Theory of planned behaviour = attitudes lead to an intention to carry out the behaviour
	Help seeking behaviour/ planned action	Theory of implementation intentions = bridging the gap between intention and behaviour (use of plan of action)
Model of care seeking behaviour [15]	Clinical variables	Presence and type of symptoms, history of prior related problem
	Denial, fear	Emotional response and apprehension directed to perceived abnormal symptom
	Utility	Beliefs about the worth of care seeking and includes expectations and values about outcomes
	Social norms	Others' (f.eg. health practitioners) about care seeking behaviour
	Facilitating conditions	Perceived influence of female friend, husband/partner, mother and female relative
	Confrontive coping	External factors having an identified provider, affordable and accessible healthcare
	Social support	Emotional, informational and tangible support
	Planful problem solving	Emotional, informative and tangible support
Prolonged Patient delay model [16]	Interpretation of symptoms at appraisal delay stage	Past benign problems and family history of breast cancer leading to misconceptions about lumps (cultural myths about lumps – painful, size, pressing caused cancer)
	Health care access and utilisation	Absence of health insurance leading to trust in or absence of provider. These also caused fewer preventative care visits.
Help-seeking behaviour and influencing factors framework [17]	Knowledge and beliefs	Identity(interpretation of symptom/symptom type), cause (risk attribution), timeline (likely duration of illness and symptom), consequences (perceived severity of symptom and impact of illness), curability, prayer and alternative therapies.
	Psychological factors	Fear, anxiety, worry, distress, uncertainty, depression
	Social factors	Role obligations, symptom disclosure
	Health service system utilisation	Perceived access, economic constraints, health insurance, perceptions of prejudice
	Health seeking habits	BSE, mammography, frequency of visits to GP

describe them. For example, 'knowledge and beliefs about symptoms', 'attitudes', 'interpretation of symptoms' and 'clinical variables' were used as constructs to describe the concept of 'attitudinal beliefs'. Various terms were also used to represent 'self-efficacy beliefs', 'normative and nor-related beliefs and activities', and 'risk-related beliefs and emotional responses' constructs. The lack of consensus in these terms gives the impression that the models are different , and it also made models comparison and assessment of their suitability for adoption difficult.

Further, even though constructs may have different theoretical and conceptual origins, and named differently, they may be measuring the same thing. For instance, there is likely to be little difference between the 'social norms', 'moral obligations', 'modelling' and 'relationship constraints' constructs.

The number and choice of concepts and constructs

All, except the Prolonged delay model (Rauscher et al., 2010), were made of between 5 and 8 concepts/constructs. The common concepts shared by many models are 'attitudinal beliefs', 'self-efficacy beliefs', and 'normative and norm-related beliefs and activities' (Table 1). There is also little commonality in the terms used to defined the constructs representing the concepts. For example, the constructs, 'health service usage habit', 'self-efficacy behaviour', 'self-confidence in detecting symptom' and 'health service habit', were used to define the concept of self-efficacy beliefs.

Four models included the 'social support' concept (Facione et al., 2002; Bish et al., 2005; Reifenstein 2007; O'Mahony et al., 2010). The role of culture was examined only in the Judgement of delay model (Facione et al., 2002). The model developers justified their choice and number of concepts or constructs with evidence obtained from their own studies and/or literature review; suggesting a possibility of bias in the choice of constructs which may be dependent on the developers' research interest. One study also included the 'denial', 'fear , and 'confrontive coping' constructs in the model (Reifenstein, 2007).

Variables used to represent constructs

Table 2 lists the variables used to operate the constructs in the models. An examination of the variables across models showed that different terms were also used to define similar constructs. An obvious example is the variables measuring knowledge of symptoms, namely knowledge of family history and pass benign problems in the Prolonged delay model (Rauscher et al., 2010). Others defined this construct as knowledge, appraisal, beliefs about symptoms, and identity. Similar observation was made of other variables. The social support construct is another example where 'emotional, informational and tangible support' variable was used in one model (Reifenstein, 2007), and relationship constraints (Facione et al., 2002), symptom disclosure (Bish et al., 2005) and role obligations (O'Mahony et al., 2010) were used in others.

Target populations and contexts

Half of the models were developed in the US and the remaining in the Netherlands, Republic of Ireland and UK. An examination of the results of tested models in Table 3 shows that the models were targeting specific populations and settings. The models in the US were tested on the African American, Hispanic and White women while the Dutch, British and Irish models were tested only on White people. One model, the Prolonged delay model (Rauscher et al., 2010), was developed for patients with a family history of cancer and personal benign cancer history. Target populations are either healthy individuals or breast cancer patients depending on the model's aim. The British model was not tested. Instead it was used to further develop an intervention to promote early presentation among older women who had had their final national breast screening and those aged 65 and over (Burgess et al., 2008).

Outcomes of models (findings of tested models)

All models were analysed using statistical analytical methods, except for the Irish model which employed the qualitative content analysis approach. The models were able to explain the variance of patient delay or intention to delay or help seeking between 16% (Reifenstein, 2007) and 40% (Facione et al., 2002). The Help seeking behaviour and influencing factors framework revealed the barriers and facilitators in help seeking for breast cancer using qualitative descriptive data (O'Mahony et al., 2010).

Discussion

The review of existing patient delay and help seeking for breast cancer models suggests a number of critical issues that need addressing. The models applied different health behavioural theories or combination of concepts from these theories. Some models were interested in the health behaviour of individuals while others were also interested in the social and cultural interactions at the interpersonal level. The choice of concepts drawn from these theories also differs across models. None of the models has yet used community and group theories in their design and given that patient delay for medical care for breast cancer requires intervention also at the community level, future models are likely to include them.

There is a lack of consensus in the terminology used to define constructs and variables, and this is also the case for constructs and variables which shared similar concepts and constructs, respectively. Previous studies also found a lack of commonalities in the terminology used in health behavioural and social science theories and models (Weinstein, 1993; Nigg et al., 2002; Noar & Zimmerman, 2005; Trifiletti et al., 2005). This made comparison and analysis of models difficult. To advance knowledge and research to understand patient delay and help seeking intention and behaviour, there is a need to reach an agreement about the names or terms used. A common conceptual language will make easy the task of theoretical integration, and for the novice researchers and practitioners, this will lighten the overwhelming task of shuffling through choices of models for adoption or adaptation.

The choice of constructs used was determined by

Table 3. Outcomes, Population and Empirical Evidence

Model	Outcomes	Population	Results
Judgement to delay model [12]	Likelihood to delay	699 healthy women volunteers from non-healthcare related community settings, San Francisco bay; black (28.2%), Latino (35.8%) and white (36%), USA Excluded: women with family history of breast cancer, and have symptoms Multiple regression analysis, bivariate analysis	Accurately predicted 40% of self-reported likelihood of patient delay, No one of the variables predominated in the explanation of variance in the likelihood to delay, Each variable added incrementally to the explained variance of the model.
Passive detection and help seeking model[13]	Paying attention to cancer symptoms; appropriately timed intention to seek help	534 healthy Dutch adults; average age = 47; 77% were women; 79% had a spouse. Multiple regression analysis	People who paid attention to symptoms had more knowledge of cancer symptoms, thought they were more able to pay attention to symptoms, and perceived less difficulties with paying attention to symptoms, more often were women and more highly educated. These variables explained 16% of variance of paying attention to cancer symptoms Knowledge of symptoms, advantages to seek help, moral obligation, anticipated regret, social norm and self-efficacy explained 20% of variance in appropriated timed intention to seek help for cancer symptoms.
Model to understand PD [14, 18]	To develop intervention to address delayed presentation by older women of > 65 years old	Literature review of existing empirical evidence; UK	Intervention developed was booklet and piloted on 50 women who recently had their final mammography screening under the UK National Breast Screening programme and 20 women over 65 years old.
Model of care seeking behaviour [15]	Variables influencing delay	48 African American women > 18 years old, self-identified breast change discovered within a year before study; average age = 40; 58% of women had a high level of education; most common employment was secretarial/clerical certified nursing assistants; New York, USA. Bivariate analysis	Denial was positively correlated with delayed care seeking; Fear is not related with denial; Confrontive coping strategies, social support strategies and problem solving strategies were negatively related with delayed care seeking, Psychosocial variable utility was not related to delay in care seeking, Participants delayed 63 days on average.
Prolonged Patient delay model[16]	Prolonged patient delay	438 female patients aged 30-79 years old; had a first primary in situ or invasive breast cancer; Chicago; African American, Hispanic, White; USA Logistic regression analysis	16% reported prolonged patient delay of more than 3 months; No significant delay by ethnicity; misconceptions were significantly associated with prolonged patient delay
Help-seeking behaviour and influencing factors framework [17]	Women's experience of finding a breast symptom and how this influenced health seeking behaviour	10 Irish women with self-discovered breast symptom; age between 25-55 years old; Republic of Ireland Qualitative interviews; content analysis	6 women sorted help promptly within 1 month, 2 women delayed between 1 – 3months, 2 women delayed over 3 months. Main barriers were denial, fear, family and work commitments and lack of knowledge in relation to family history, and risk and perceived incurability of breast cancer. Main facilitators were a pragmatic outlook fear, symptom disclosure to another person, confidence in the health services and overall knowledge about breast symptoms and their associated risks and the importance of early detection.

previous research conducted by model developers and literature review, as well as by the target population and settings. The number of constructs in existing models ranged from 2 to 8 and appears to fit the requirement of being parsimonious in model development (Glanz et al., 2008). However, not all the models' internal validity had been tested.

No individual construct in the models was found to be more influential than others in explaining help seeking behaviour and/or influence behavioural change. The Judgement of delay model found that cumulatively their constructs explained 40% of patient delay. In the Passive detection model, the variables 'symptoms knowledge, being female and highly educated' together explained 16% of variance of paying attention to cancer symptoms, while the variables 'symptoms knowledge, advantages

to seek help, moral obligation, anticipated regret, social norm and self-efficacy' explained 20% of variance in appropriated timed intention to seek help for cancer symptoms. The poor results indicate that there are other important influencing factors that have not been accounted for in these models. This also implies the likelihood that more models in this field will be proposed in the future to fill in the gap.

Current models appeared to be developed for specific population sand settings, and therefore, are not possible to generalise to another setting. However, significant constructs in these models may be taken and integrated to form new model appropriate to another setting or context.

In conclusion, existing patient delay and help seeking models for breast cancer were tested and yielded some degree of confirmation of their ability to explain this behaviour, to sufficiently accept rather than reject the models. However, a lack of consensus in the terminology used to define constructs and variables, and variation in the combination of concepts, constructs and variables used to build the models, made it difficult to assess the appropriateness and generalisation of models to another population and context. Greater consensus and a shared conceptual language will pave the way to advance knowledge and research in this field.

Acknowledgements

The author declares no conflicting interest.

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