AN INVESTIGATION OF THE INFORMATION NEEDS AND BEHAVIOURS OF PARENTS OF CHILDREN WITH CANCER

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This dissertation was submitted in part fulfilment of requirements for the degree of MSc Information and Library Studies

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DECLARATION

This dissertation is submitted in part fulfilment of the requirements for the degree of MSc of the University of Strathclyde.

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ABSTRACT

Approximately 1500 children a year are diagnosed with cancer in the United Kingdom (Lennox, 2012). While survivorship of childhood cancer has increased significantly, the childhood cancer experience (including symptoms and treatment) has a substantial affect on the daily life of families and can have lasting emotional and psychological effects for all involved. Several studies, (including Maurice-Stam, et al, 2008, and Norberg, A., Pöder, U., von Essen, L., 2011) have shown a link between the ability to search for and use information during the childhood cancer experience and the coping abilities of parents of children with cancer (PCWC) and the development of post-traumatic stress disorder (PTSD).

This study identifies common information needs and preferences of PCWC. An emergent methodology of analysing and coding archived posts from online discussion forums was employed. In total, 57 posts were included for analysis from the Macmillan and CLIC Sargent cancer support websites. While the literature review suggests that the most commonly sought type of information by PCWC are *treatment, disease,* and *practical/daily life* information, the gathered posts indicate that PCWC primarily use online discussion forums in order to share *similar experiences* information with other PCWC. In addition to the quantifiable data that is presented, several of the posts have also been analysed using established models of ISB in order to identify and examine evidence of uncertainty, Information Poverty, and Everyday life information seeking (ELIS) among PCWC.

The recommendations for future study focus on an ethnographic study that would follow families through the childhood cancer experience in order to track what events prompt changes in information needs and how PCWC react to uncertainty. The priority recommendation for services is to create and promote cancer-type specific discussion forums for PCWC. Service recommendations also discuss the use of information prescriptions and providing positive information experiences early within the childhood cancer experience in order to encourage PCWC to actively seek and use information throughout the childhood cancer experience.

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1. Introduction

1.1 Background

Approximately 1500 children are diagnosed each year with cancer in the United Kingdom (Lennox, 2012). Although 8/10 young cancer patients now survive past five years, the effect of diagnosis, treatment, and post-treatment experience of cancer affects many parents and families throughout all of the UK. With the diagnosis of childhood cancer, parents/carers are inevitably called upon to seek and use information which they've not sought or used before; ranging from highly technical medical terminology to various forms of emotional/practical support during the childhood cancer experience. One parent of a child with cancer (PCWC) described the early childhood cancer experience as:

> "The diagnosis throws the family into a crisis. Immediate decisions must be made on doctors, hospitals, and treatment plans. To make informed decisions massive amounts of information are needed, at a time when parents are least able to absorb facts. Parents have an almost painful need for information."
>
> (Kelly and Porock, 2005, pp. 58).

In addition to being concerned over their child's condition, PCWC typically assume the role of managing their child's care, including making decisions regarding treatment and understanding the course of the disease. The ability of PCWC to actively seek and employ information is correlated with their coping skills during the childhood cancer experience, and can have an effect on the care of the child and the family during the cancer experience (see Da Silva, Jacob,and Nascimento, 2010, Norberg, A., Pöder, U., von Essen, L., 2011, and Norberg, Lindblad, and Boman, 2005).

1.2 Research proposal

This MSc dissertation study proposes to examine the information needs and seeking behaviours (ISB) of parents/carers of children with cancer. Previous studies have mainly focused on the medical information needs of PCWC, from the perspective of medical professionals. By examining archived discussion threads on cancer support websites, the main goal of this study is to identify what types of information (treatment, emotional support, practical/daily life) PCWC actively seek and if they show any preferences while searching for information. In addition, individual posts will be analysed and compared to ISB models to ascertain if specific information behaviours are present (such as information poverty) as well as question if a typical process for PCWC ISB can be established.

Ultimately, this study aims to examine the processes and accompanying feelings/emotions that parents/carers undertake as they seek, and use information, in order to improve services to support parents and families during the cancer care process. This study will not only inform the information science community, but hopes to inform the medical and social care community by offering insight into the experience of parents/carers as they seek information on behalf of an ill child.

1.3 Background literature

A literature review of the general childhood cancer experience examined the effect of childhood cancer on the family and how parents/carers seek, analyse, and use information in order to manage the care of the child.

The effect of childhood cancer on the family is multi-dimensional. The quality of life for families is affected significantly by time and money constraints, as well as added psychosocial burdens (Tsimicalis et al, 2011). Family structures are altered by the experience, as often one parent takes the lead in treatment decision making (TDM), while the other parent is left to manage the rest of the family (Kelly and Ganong, 2011). In addition, marital relationships can be affected by the childhood cancer experience as daily life is interrupted (Long and Marsland, 2011).

The literature regarding information experiences of parents managing the care of a child indicated that although parents sourced information from a variety of sources, they were only likely to follow advice from medical professionals and other parents (Mosely et al, 2011). However, the relationship parents had with medical professionals significantly influenced how reliable they perceived information to be (Starke and Möller, 2002). The role of the parent as ‘advocate’ for the child was discussed, as parents are called upon to gather and analyse information, and make medical decisions regarding treatment on behalf of a child. The importance of offering ‘family-centered care’ in diagnosis and throughout the phases of the childhood cancer experience, particularly in information experiences, was emphasized (Holm et al, 2003).

While the medical and social science disciplines have attempted to understand the role of parents/carers within the management of childhood cancer treatment, previous studies have generally not studied the processes and techniques that parents employ to gather, understand and employ information. Essentially, previous literature has failed to address the fundamental questions of ISB: what information do parents seek, what prompts different information searches, are there preferences for information sources, and how do parents evaluate the usefulness/reliability of information sources? The article 'Cancer patients' information needs and ISB: in depth interview study' (Leydon et al, 2000) examined many of these fundamental questions of ISB for adult cancer patients. The findings indicate that a pattern of seeking information during cancer exists. Initially, patients want all available information relating to their disease. However, throughout the course of the illness, patients desire less information, and even reject information prior to the end of treatment. While the researchers' analysis presented several rationales for this pattern, it is unclear if this pattern could be established in parents seeking information in order to manage treatment of an ill child.

1.4 Research questions

Based on the evident gaps in the initial literature review regarding information experiences of PCWC, the following research questions are proposed:

- What types of information (medical or support) do PCWC search for?
- What information preferences (including source and format) do PCWC exhibit?
- What experiences facilitate uncertainty in PCWC, and how can information services help diminish/control uncertainty in the childhood cancer experience?

Because of the time and resource limitations of this study, this is considered a pilot study of the information seeking patterns and processes of PCWC, and is not an exhaustive examination of the ISB of PCWC. The design of this study will dictate that the research questions be focused on information needs as reported in online communities (discussed in section 3.1).

1.5 Current initiatives

Although childhood cancer support services have been previously deemed ‘ad hoc’ (Mitchell, Clarke and Sloper, 2006) across the UK, several initiatives in cancer support have been established in the past few years to improve cancer support consistency. The two main initiatives are the International Confederation of Childhood Cancer Parent Organizations’ (ICCPO) “Guidelines for standards of treatment and care” (2002) and the Coalition government’s “Improving outcomes: a strategy for cancer” (2011).

The ICCPO document draws upon international rights established by the United Nations to define standards of care for children with cancer. Intended as an international document, the “Guidelines for standards of treatment and care” (2002) recognises that access to and quality of medical treatment will vary greatly between countries. While the main priority listed in the document is to improve speed of diagnosis and medical care throughout the world, the document emphasizes that core to improving care is “that families should have access to information throughout the process” (ICCPO, 2002, pp. 4) regarding all aspects of the cancer experience, and parents should be encouraged to “retain their parental role” (ICCPO, 2002, pp. 3).

Along a similar line, “Improving outcomes: a strategy for cancer” (Department of Health, 2011) by the Coalition government ultimately seeks to increase the number of cancer survivors by 5000 each year beginning in 2014. The role of information provision in reaching this survivorship goal, as well as improving the cancer experience for those undergoing treatment, is shown throughout the document – particularly in the discussion of increasing early diagnosis through educating the public. The document calls for several specific measures (such as ensuring Information Standards are met and meeting NHS information guidelines). Specifically addressing information provision, the document states that “Information will be central to the drive for better outcomes” (Department of Health, 2011, pp. 18) and that identifying “the gaps in information on health outcomes [is] crucial to ensuring patients are empowered” (Department of Health, 2011, pp. 3). The strategy reflects the “Big Society” ideals of the Coalition government by encouraging partnerships between the NHS and charitable cancer support organisations in achieving the goals described.

The ICCPO and current Coalition government’s initiatives highlight the significance of information provision during the cancer experience, and indicate that information provision (responding directly to the needs and behaviours of users) is a priority for cancer support organisations. This MSc project will help to identify what types of information PCWC typically search for. The conclusions and recommendations section of the MSc dissertation will make specific recommendations for support organisations in order to better meet the goals set forth by current initiatives.

1.6 Learning outcomes

This study aims to identify common information needs and preferences of PCWC, as reported by PCWC themselves. A thorough literature review of information seeking behaviour in general, and PCWC experiences will be conducted. An emergent methodology (analysing archived discussion threads) will be employed, and the researcher will analyse the usefulness and limitations of the methodology. Information need types will be quantified, reported, and compared to the literature review. Individual discussion posts will be analysed qualitatively and compared to established models of information seeking behaviour, to identify information behaviours of PCWC, and their possible causes, in order to gain a richer perspective of the childhood cancer experience for PCWC. The conclusions and recommendations section will summarize the quantifiable and qualitative data, and make specific recommendations for further research into PCWC ISB, as well as how to improve medical and support organisations based on the data from this study, and the initiatives addressed in section 1.5.

2. Literature Review – Introduction

The report of the reviewed literature will begin with a brief explanation of relevant models and concepts of information seeking behaviour (ISB), namely: Kuhlthau's Information Seeking Process (ISP), Chatman's Information Poverty, Wilson's Model, and Savolainen's Everyday Life Information Seeking (ELIS). Because the childhood cancer experience affects all aspects of families' lives, the theories of ISB were selected based on their application of social and psychological theories, their ability to examine a variety of variables of ISB, and their examination of the link between information seeking and coping/uncertainty. The concepts reviewed in the ISB literature will then be applied to literature focusing on the general cancer experience of parents of children with cancer (PCWC), and specifically on information experiences of PCWC.

Referring to the general childhood cancer experience, one group of researchers stated:

> "The diagnosis of childhood cancer is one of the most intense, disruptive, and enduring experiences that parents can have. The often unexpected and life-threatening diagnosis and the initiation of invasive medical treatment and its sequelae interfere with the entire family's normal activities and routines for a long period of time and impose stressors of varying duration, predictability, and impact" (Vrijmoet-Wiersma et al, 2008, pp. 694).

Hence, it is important for the literature review to include a discussion of research that focuses on the general cancer experience of PCWC, how the cancer experience affects PCWC psychologically, and trends in how PCWC manage the care of their child and their everyday family life. Very little has been written specifically addressing the ISB of PCWC. What research regarding the ISB of PCWC was available was primarily written from either a social science (psychology) or medical perspective and has been interpreted from an information science viewpoint, focusing on the research questions identified in the introduction. During the review of literature regarding the cancer experience of PCWC, general themes were identified and compared with the chosen models of ISB, specifically: uncertainty, coping skills, avoidance, negative experiences, and attempts at parental education services.

2.1 Models and Concepts of ISB

Information-seeking is a general term that describes how individuals search for and apply information in order to accomplish tasks or satisfy an information need. Studies are typically conducted on information-seeking in order to improve how information is delivered to individuals, including computer-based information retrieval programs, and through information support agencies. Case describes information-seeking as

> "behaviour that occurs when an individual senses a problematic situation or information gap, in which his or her internal knowledge and beliefs, and model of the environment, fail to suggest a path towards the satisfaction of his or her goals" (Case, 2007, pp. 333).

Information-seeking behaviour (ISB) not only reflects how individuals search for information, but also what factors either lead them to initiate a search or prevent them from searching. ISB also considers how individuals employ and share information, what preferences individuals' exhibit, and how individuals assimilate new information into their personal point of view (Kuhlthau, 1991, pp. 361).

An underlying theory of many ISB models is Brenda Dervin's Sense-Making theory, which models the process individuals undertake either consciously or unconsciously to "make sense" of uncertain situations. Dervin describes Sense-Making as "a philosophically derived approach for studying communication as communication" (Ohio State University, 2012). The theory is purposefully inter-disciplinary (as information needs and communication exist in all disciplines) and relies heavily on metaphors (particularly journey metaphors) to model individuals moving from uncertainty to understanding (Dervin, 1999, pp. 728). Dervin's work forms the basis for many ISB models because it emphasizes the user's needs and perceptions during the information experience.

Over the past thirty years several models of ISB have been proposed as abstractions of human information behaviour. Studies of ISB are typically conducted on communities of individuals that share common information needs, such as students, prisoners, patients, etc. The major concepts behind four commonly cited models of ISB are discussed below.

2.1.1 Kuhlthau's Information Seeking Process (ISP)

Kuhlthau's Information Search Process (ISP) model emphasizes the experience of the user in the search process, and is concerned with the "various feelings that information seekers experience in each stage of the search process" (Wang, 2011, pp. 23) and how user's feelings and thoughts lead/dissuade users from further action. Kuhlthau's stages of initiation, selection, exploration, formulation, collection, and presentation aim to model the process of searchers moving from uncertainty to understanding (Kuhlthau, 1993). Kuhlthau identifies two sources of uncertainty: the user not knowing what to look for, and uncertainty over how to use technical instruments (such as databases or website functions) (Kuhlthau, 1993). As users are "exploring," if too much information seems inconsistent, and if users become frustrated with systems, users "may be inclined to abandon the search altogether at this stage" (Kuhlthau, 1991, pp. 7-8). Kuhlthau goes on to examine the link between "successful" information searches and decision making. Kuhlthau quotes Whittmore and Yovits stating, "To effect a meaningful analysis of pragmatic information, one must look in detail at that which makes decision-making such a challenging and oftentimes agonising activity: uncertainty (Whittemore and Yovits, pp. 224). Thus, in order to proceed through the information search process, uncertainty must be diminished at each stage, and the process should ultimately lead to a decision making task.

Finally, Kuhlthau emphasises that success (diminished uncertainty) in the early stages of her model (initiation, selection, exploration) will encourage information users to continue to search for and use information. Uncertainty is to be expected in the early stages of a search process, and is actually the motivating factor behind initiating a search. However, if uncertainty persists into the later stages of Kuhlthau's model (into the formulation stage), the user's confidence will diminish and anxiety will increase (Spink et al, 2002.) Kuhlthau concludes that users that were experienced with the stages of the information seeking process "had a tolerance for the ambiguity and uncertainty of the earlier stages," developed a sense of ownership over the process, and were more likely to learn from the process (Kuhlthau, 1991, pp. 369).

Kuhlthau's "uncertainty principle" included in her ISP could be usefully applied to a study of PCWC. Although uncertainty over treatment results and ultimately the course of the disease will always exist, studying how to assist PCWC in reducing their uncertainty over medical and non-medical information through various resources would have positive effects on PCWC optimism and the ability to make decisions.

2.1.2 Chatman's Information Poverty

Influenced by Brenda Dervin's work on the "information poor" (Dervin, 1989, pp. 219), Chatman's ethnographic investigations provide insight on information behaviour within communities. Some of Chatman's most cited information investigations include examining the information worlds of janitors, retirement-age women, and female prisoners. Chatman's Information Poverty theory explores how individuals, and communities of individuals, not only exhibit information needs, but also do not possess the ability or skills to gain the required information. In addition, some of the behaviours that individuals exhibit hinder their ability to gain and use information. Chatman classifies individuals that are information poor as "the outsiders" and contrasts their information, skills, and community positions with "the insiders." Typically, "outsiders" are economically and socially poor, while "insiders" hold a position of power within the community or relevant situation, which affects their relative abilities to search for and use information (Chatman, 1996, pp. 193). Chatman's six propositions further define information poverty.

Proposition 1: People are defined as information poor perceive themselves to be devoid of any sources that might help them.

Proposition 2: Information poverty is partially associated with class distinction. That is, the condition of information poverty is influenced by outsiders who withhold privileged access to information.

Proposition 3: Information poverty is determined by self-protective behaviours (see below) which are used in response to social norms.

Proposition 4: Both secrecy and deception or self-protecting mechanisms due to a sense of mistrust regarding the interest or ability of others to provide useful information.

Proposition 5: A decision to risk exposure about our true problems is often not taken due to a perception that negative consequences outweigh benefits.

Proposition 6: New knowledge will be selectively introduced into the information world of poor people. A condition that influences this process is the relevance of that information in response to everyday problems and concerns.

Chatman also identifies four self-protecting behaviours that reinforce information poverty: secrecy, deception, risk-taking and situational relevance (Chatman, 1996, pp. 193). Secrecy in the information poor is based on the premise that “information about personal experiences is secret information” and needs to be protected in order to protect one’s self (Chatman, 1996, pp. 195) from real or imagined threat. Chatman cites the experience of retirement age women not sharing their medical concerns with staff or even family members, as the women are afraid of the repercussions. Deception is related to secrecy, and is a self-protecting behaviour meant to keep personal information and experiences private. However, deception also implies that active steps are being taken in order to deceive other parties. Risk-taking is a self-protecting behaviour that evaluates when it is necessary to risk sharing personal information/experiences in order to gain information or support; it weighs the relative advantages against perceived risks. Finally, situational relevance evaluates the “utility” or “usefulness” of information in a specific situation. Chatman argues that the information poor are less likely to actively seek information unless it is deemed “useful” or that they have the ability to find and use the information.

While it would be inappropriate to classify all PCWC as information poor, examining the behaviours of PCWC could indicate the occurrence of information poverty in specific situations. Studying the experiences of PCWC could help information and support professionals identify what factors lead to information poverty (and related self-protecting behaviours) and how best to serve marginalised individuals and families.

2.1.3 Wilson's Model

Wilson's 'Information-seeking Behavior Model' is unique by directly adapting theories from other fields (including decision making, psychology, innovation, health communication, and consumer research) into a model of ISB (Case, 2007, pp. 136). Wilson's model is composed of six stages: Context of information need, activating mechanism, intervening variables, activating mechanism (2), information-seeking behaviour, and information processing and use. Wilson also accounts for different types of searching – such as a one-time search, or an on-going search. Arguably a very complex model, Case suggests that Wilson's model asks the following questions (Case, 2007, pp. 136):

- Why some needs prompt information seeking more so than others (stress/coping theory, from psychology)
- Why some sources of information are used more than others (risk/reward theory, from consumer research)
- Why people may, or may not, pursue a goal successfully, based on their perceptions of their own efficacy (social learning theory, from psychology).

While Wilson's model is complex, particularly with the in-depth application of theories from other fields, these three questions identified by Case are directly applicable to the PCWC information experience. Rephrased to be adapted to the childhood cancer experience, Wilson's model could be used to study:

- Why some cancer events (diagnosis, new symptoms, treatment) prompt information seeking more so than others?
- Why do PCWC prefer some sources of information? Why are medical professional relied upon for non-medical information?
- Why do PCWC choose to, or not to, be actively in charge of their child's care, based on their perceptions of their own efficacy?

2.1.4 Savolainen's Everyday Life Information Seeking (ELIS)

While many previous studies of ISB focused on work-related tasks, Savolainen's everyday life information seeking (ELIS) studies how individuals seek information in non-formal settings, that are "not constrained by goals and requirements" (Wang, 2011, pp. 20). Although the line between work and non-work activities is difficult to define, and there are some crossovers, ELIS is concerned with how people seek and use information for their daily personal lives, including leisure activities. Some examples might be: how individuals search for and book a holiday, how they conduct grocery shopping, or how individuals research a hobby.

ELIS is typically not concerned with single information experiences, but rather looks at how individuals interact with information in general, and emphasizes "the role of social and cultural factors that affect people's way of preferring and using information sources" (Savoleinan, 2005, p 143). The ELIS model accounts for personal and situational factors, as it intends to examine a "broad scope of human lives" (Case, 2007, pp. 132) and how a variety of individuals interact with information. Savoleinan's model is primarily an attempt to show the "mastery of life," or how individuals keep order of events and information and make sense of experiences; similar to Dervin's Sense-Making theory. It is important to note that the model is not intended to generate theories of behaviours, but rather to "provide a framework or guidance in considering different factors relevant to everyday information needs and seeking" (Wang, 2011, pp. 20).

Applying the ELIS model to a study of PCWC information experiences could indicate how PCWC seek and use information in order to maintain a "mastery of life" and control over their everyday lives.

2.2 General cancer experience of PCWC

Although the survival rate of childhood cancer has significantly improved "childhood cancer is a dramatic event that affects the daily life and emotional well-being of all family members" (Maurice-Stam, et al, 2008, pp. 448). Family schedules, professional lives, finances, relationships and roles are all altered by the childhood cancer experience. Not only are parents called upon to manage the medical care of their child, but PCWC are also the main source of emotional support for their child, and act as a filter for the cancer experience for others. Research (see Rodriguez et al, 2012, and Stuber et al, 1994) has shown that a childhood cancer experience has lasting emotional and psychological implications for all of the family members, particularly mothers.

The past decade has seen a large portion of research focused on the development of post-traumatic stress disorder (PTSD) in PCWC (Norberg, A., Pöder, U., von Essen, L., 2011, Rodriguez et al, 2012, and Alderfer and Navsaria, 2009). Researchers have not only been interested in what events during the cancer experience stimulate PTSD, but also how long PTSD will last beyond the cancer experience, and what factors enable parents to successfully avoid developing PTSD. One of the key questions raised by researchers has been “What are the different sources of stress during the cancer experience, and how can they be minimized or controlled?” Obviously, having a seriously ill child is a significant source of stress. However, other sources of stress have been found to be equally, if not more, significant in the development of PTSD in PCWC, such as: changes in family relationships (particularly between spouses), explaining the disease to others, and uncertainty over the disease, treatment, and outcome of the cancer experience (See Fotiadou et al, 2008).

Uncertainty affects PCWC in several ways. Several studies found that parents who were more proactive in their child’s care were less likely to develop PTSD (see Maurice-Stam et al, 2008). Proactive parents also exhibited the ability to actively search for information, and apply the information in problem-solving situations (Norberg., Linblad, and Boman, 2004). Furthermore, it has been shown that uncertainty was a significant source of strain on familial relationships, and could even affect the level of care and support offered to the sick child (Best et al, 2001).

The establishment of coping skills early in the childhood cancer experience has also been shown to have a significant impact on the development of PTSD in PCWC. A study on the impact of childhood cancer on parents’ relationships (Da Silva, Jacob, and Nascimento, 2010) showed that the first six weeks of the cancer experience were crucial to developing successful coping strategies and establishing patterns of how to manage the disease and altered daily family life. Successful coping strategies include both “problem-solving strategies” (dealing with controllable circumstances) and “emotion-focused strategies” (dealing with uncontrollable circumstances) (Norberg, Linblad, and Boman, 2004, pp. 972). Both forms of coping strategies are useful within and beyond the cancer experience, and can be learned to some degree.

Research has examined the long-term effects of the childhood cancer experience on the emotional state of PCWC. According to a longitudinal study by Boman, Lindal, and Bjork (2003), while most PCWC have a reduced level of stress following the initial diagnosis and treatment phase, “data suggest that a number of parents still experience increased distress and exhibit stress symptoms even after [a] long period of time” (Boman, Lindal, and Bjork, 2003, pp. 137).

Coping behaviours, which directly influence the development of PTSD and help control emotional trauma during the childhood cancer experience, are widely linked with information seeking behaviours, and successful information experiences (Norberg, Lindblad, and Boman, 2005). Studying the information experiences of PCWC could provide researchers additional information regarding the formation of PTSD and uncertainty over the childhood cancer experience. All of the reviewed models of ISB derive aspects of their theories from psychology and sociology. An investigation into PCWC ISB could indicate what prompts information searches (especially and application of Wilson’s model and Kuhlthau’s ISP), and what experiences heighten/diminish uncertainty (Kuhlthau’s uncertainty principle).

2.3 Information experiences of PCWC

To date, little research exists on the ISB of PCWC throughout the course of the childhood cancer experience. However, several studies describe trends in information experiences of PCWC, and investigate their impact on the overall childhood cancer experience for the family. Although not from an information science perspective, several studies have also been performed on how the information seeking process contributes to uncertainty and affects parental optimism.

Avoidance behaviour, while not as common among PCWC as active-problem solving, is one of the key concepts of study in parental optimism (Norberg, Lindblad, Boman, 2005). Among other avoidance behaviours, the avoidance of information has been shown as being an indicator of how parents are coping with the childhood cancer experience. Leydon et al's (2000) 'Cancer patients' information needs and ISB: in depth interview study' indicated that a pattern of information avoidance does exist in the later stages (post-treatment) of the cancer experience. While the researchers' analysis presented several rationales for this pattern, it is unclear if this pattern could be established in parents seeking information in order to manage treatment of an ill child, and if information avoidance is more prevalent during palliative care. From an ISB perspective, the diminution of information seeking could either be an indication of the patient/PCWC having gained an adequate level of understanding, or the patient/PCWC feeling overwhelmed with new information needs, and abandoning information seeking due to an inability to manage uncertainty (see section 2.1.1 Kuhlthau's Information Seeking Process).

In connection to information avoidance, negative information seeking experiences (such as being given false/incomplete information) has been shown to affect parental optimism, and other coping strategies. Not only does inaccurate information affect treatment decisions made by PCWC, it can also impact the relationship between PCWC and the medical professionals administering care to the child. The relationship between PCWC and medical professionals is further tested by the bedside manner of the professionals, particularly their ability to convey empathy (Zwaanskwijk et al, 2011). Medical professionals' handling of sharing information ultimately affects the child's and the PCWC's feeling of security regarding the care of the child (Anderzén-Carlsson et al, pg. 320). The impact of medical professionals' delivery of information could have a direct link with Chatman's Information Poverty theory. PCWC could feel marginalised based on their experiences with medical and support professionals, which in turn could affect their future information searches by PCWC employing self-protecting behaviours.

Some information preferences of PCWC have been investigated. A postal survey of 303 PCWC in the United Kingdom conducted by the University of York in partnership with CLIC Sargent (Mitchell, Clarke, and Sloper, 2006, and Clarke, Sloper and Mitchell, 2004) indicated that PCWC are generally satisfied with the medical information provided to them on diagnosis (roughly 80% satisfaction rate). Similarly high positive responses were reported for parents' satisfaction with "treatment explanations" and "care involvement." Interviews associated with the study also indicated the need for repetition of information, and that parents typically preferred to receive information (such as test results) verbally, but to also receive written information at the same time in the consultation. A large portion of parents stated they wanted additional help searching the internet for additional information, a list of recommended childhood cancer websites, and additional ways to share disease-related information with family members (such as with a video explaining the cancer experience and procedures). It should be noted that the study conducted by Mitchell, Clarke, and Sloper questioned PCWC regarding a variety of aspects of the general childhood cancer experience (including hospital facilities, support organisations, etc.) and did not focus on information experiences of PCWC. Likewise, the study questioned "satisfaction" rates, and did not account for emotions felt by the PCWC during information experiences, or describe the process by which PCWC seek/use information. Mitchell, Clarke, and Sloper's response rates are questionable as their methodology did not reflect a true randomised sample. Although Mitchell, Clarke, and Sloper's reported satisfaction rates appear remarkably high, other studies (including Shilling, Jenkins and Fallowfiled, 2003, and Zachariae et al, 2003) investigating satisfaction rates of cancer patients and their families indicate that patients show high satisfaction rates with practitioners that exhibit "interpersonal skills such as communicating empathically about the patient's experiences may have the largest effect on patient satisfaction" (Shilling, Jenkins, and Fallowfield, 2003, pp. 600).

There is also evidence that although differences in the type of cancer and time since diagnosis does not affect communication preferences of PCWC, the previous knowledge of PCWC does affect their information preferences and behaviours (Zwaanskwijk et al, 2011) – which could have a comparison with Wilson's model of antecedents. Findings from studies (including Zwaanskwijk et al, 2011) indicate parents are adequately satisfied with the information provided to them through medical professionals, but have difficulty searching for information on their own, which can cause uncertainty and anxiety. Also, the research indicated only investigated PCWC preferences and assessment of the delivery of disease-related information. Research regarding the information preferences of PCWC regarding non-disease-related information (such as emotional support, financial services, etc.) has been understudied.

Attempts at providing parental education during the cancer experience have been experimented with. An early study (Rudolph et al, 1981) detailed the development of a successful formal education program for PCWC. Consisting of a twelve-hour course over several weeks, the program focused on social, psychological, and disease-related information sources for parents. One of the key concepts of the course was encouraging parents to use resources within their communities to find useful information and support. Obviously this study predates the general availability of the internet, and PCWC information seeking practices have changed considerably since the study. However, the importance of empowering PCWC with various types of useful information to be used during the childhood cancer experience has been shown more recently. Mercer and Ritchie (1997) argued that the goal of parental education in childhood cancer should emphasise that “The role of the health care provider is to help [PCWC] to be empowered but not to foster dependency on professional helpers or systems [...and] interventions with families should help them access resources through their formal and informal social networks” (Mercer and Ritchie, 1997, pp. 331). An investigation of the information needs and preferences of PCWC could aid medical and support professionals in their roles of supporting PCWC becoming more independent in the management of the care of their child, by indicating what types of information PCWC seek, and what encourages their use of information sources. Encouraging PCWC to engage with childhood cancer support organisations and communities would help to negate Information Poverty, and encourage PCWC to achieve a “mastery of life” during the childhood cancer experience by empowering them with the necessary information skills to manage their uncertainty.

2.4 Literature review discussion

The literature regarding the general experiences of PCWC showed that a major concern for researchers is the development of PTSD in PCWC. The research also suggested that helping parents establish coping strategies early in the cancer experience and encouraging parents to be proactive in the care of their child had a direct effect on the development of PTSD in PCWC. The ability to successfully search for and apply information was identified as a coping strategy and enabled parents to be proactive. Parents showed a general satisfaction with the disease information they received from medical professionals. However, the literature also indicated that parents have additional information needs (emotional support, financial, etc) that are not being adequately met. Furthermore, it appears that PCWC rely on medical professionals for non-disease information instead of searching through alternative sources. As was shown through the literature review of the general childhood cancer experience, while major advances have been made in the treatment of childhood cancer, evaluation of psychosocial support is less developed (Clarke, Mitchell and Sloper, 2004).

The variety of information and support needs identified in the literature review can be summarised as treatment information, disease information, information on impact on relationships, providing information to others, practical/daily life information, and general social and emotional support needs. These six types of information needs will form the basis of code categories employed during this study (see section 3.2.2).

Ultimately, the goals of studying the ISB of PCWC should be to encourage PCWC to use community resources for support and information early in the cancer experience and help PCWC to feel empowered in understanding and managing their child's disease. The methodology of analysing archived discussion threads (see section 3) aims to give PCWC a voice and help describe specific information experiences from their point of view, in order to identify information needs and preferences to develop future services.

3. Methodology – Introduction

The following sections will outline the chosen methodology of research using archived forum posts. Rationale for choosing the methodology, including examples of previous applications of the methodology, will be discussed. How the methodology will be applied will be described. Finally, any anticipated conflicts between the methodology and research questions will be analysed.

3.1 Methodology – Rationale

As was shown by the introduction and literature review, the topic of study for this dissertation is the information needs and preferences of PCWC, and how best to support PCWC in searching for and applying information in the management of the care of their child. The following research questions have been raised:

- What types of information (medical or support) do PCWC search for?
- What information preferences (including source and format) do PCWC exhibit?
- What experiences facilitate uncertainty in PCWC, and how can information services help diminish/control uncertainty in the childhood cancer experience?

Gaining an understanding of the childhood cancer experience from the parent's perspective is essential to investigating these research questions. Initially a focus group involving semi-structured questions about PCWC information needs and resources was considered. However, due to the limited time period of this study, and difficulty of establishing research partners (including contacting three local cancer organisations that all declined) in order to recruit participants, the use of a focus group was abandoned as the chosen methodology. In order to gather a sample of parental experiences for analysis in the short time period of the study (June – Aug 2012), historical online forum research was chosen as the methodology.

Historical research is a largely qualitative methodology that focuses on "reconstructing the past...to investigate processes, behaviour, individual events or patterns of use" (Pickard, 2007, pp. 142). The term "historical" does not necessarily refer to a specific time period, but rather refers to the fact that the data was created prior to the study, and not specifically for the intention of being studied. The primary tasks involved in historical research are identifying, locating and retrieving, and analysing data that already exists. Historical research is best applied when analysing specific problems, rather than gaining a general perspective. Likewise, because historical research primarily employs a grounded theory approach and investigates emerging patterns, the methodology relies heavily upon the researcher's personal interpretations of historical data and requires the researcher to establish and maintain specific search and analysis criteria in order to remain objective (see Pickard, 2007, pp. 142-143).

An emerging form of historical research is analysing archived posts on internet support forums. Because of their ability to connect geographically distant people, and maintain anonymity, internet support forums have become a popular source for individuals to seek information and share their concerns (see Ridings and Geffen, 2004). For example, Meier et al (2007) reported that participants in ten cancer mailing lists typically discussed experiences with medical professionals and treatment information on online discussions. Forums can provide candid, firsthand accounts of experiences and often reflect emotions experienced by the participant. A recent employment of historical research of internet support forums includes Hassler and Ruthven's (2011) investigation of examples of information poverty being exhibited on internet support forums. Using Chatman's six propositions regarding information poverty, Hassler and Ruthven identified and coded posts to information support forums. Their findings indicated that users of internet support groups who exhibited information poverty often hid their information needs from "people close to the poster who should usually be able to help" – including healthcare professionals. Likewise, users felt that they were "unable to approach anyone at all about their problems" (Hassler and Ruthven, 2011, pp. 8). As was shown in the literature review, Chatman's information poverty could be applied to the experiences of PCWC, making it valid to study PCWC use of internet support groups as parents are unsure where else to search for information and support, while potentially remaining secretive and employing self-protecting behaviours. Furthermore, childhood cancer internet support forums are typically linked with information/support websites which PCWC are likely to search, and help establish a community of PCWC with similar experiences, regardless of geographical distance (Rodgers and Chen, 2005).

Savolainen (2011) has also recently employed the use of studying archived forum and blog posts in his study of information seeking and provision of Finnish sites devoted to depression in order to study the use of blogs and internet forums in everyday life information seeking. Around 40 discussion threads focusing on depression from the forum Suomi24 were analysed to identify common information searches and how posters answered each other's questions. There was no time limit on the discussion threads, but threads were required to have at least 10 postings in order to be deemed viable. The threads were analysed quantitatively to describe overall information needs, as well as qualitatively to showcase specific examples of information needs. Posts were coded through an iterative process in order to identify categories of information needs, with individual postings being allowed to be sorted into multiple categories. Categories included: factual information about depression, opinion or evaluation of an issue, or practical treatment options. Savolainen's findings indicated that blog and forum users typically posted in order to gain an opinion or to explore an experience, but "needs for factual information and procedural information about possible ways of action were presented less frequently" (Savolainen, 2011, pp. 863). The methodology provided by Savolainen is directly applicable to this study of the information needs of PCWC as it shows how a variety of threads can be coded to search for common types of information requests (either practical, opinion, or treatment focused).

Hassler and Ruthven's (2011) and Savolainen's (2011) studies show how the employment of historical online forum posts is a viable methodology for studying users' information needs, preferences, as well as behaviours. Evaluating archived posts is also valid because of the reasons why posters choose to use forums. Studies into computer-mediated communication (CMC) over the past two decades have indicated that users of online support forums initially post not only to maintain anonymity, but also to receive insightful, informal, and personal communication (see Walther, 1996). Analysing the posts of PCWC should show candid and honest information needs as they communicate and share experiences with each other in a supportive community. The data collected will be unsolicited information from the perspective of PCWC, including information needs about non-medical and support needs, which has shown to be understudied by the literature review (see Mitchell et al, 2006, Kelly and Porock, 2005, and Rudolph et al, 1981).

Because the chosen methodology is based on data that is already in existence and may not specifically address research questions, and because the researcher will not be communicating with PCWC directly, the research questions of this study have been modified slightly. The modified research questions focus more on general information needs of PCWC, which are anticipated to be reported in community forums:

- Can common information needs of PCWC be identified? What are these common information needs, and what categories of information needs (treatment, support, etc) are most prevalent?

- What behaviours (secrecy, deception), emotions (anxiety, confusion) and preferences do parents of PCWC exhibit and report as they search for information?

3.2 Methodology – Application

The methodology will be applied in three phases: collection of sample posts, identification of information need, and (where applicable) analysing posts for information behaviours and preferences.

3.2.1Phase one: Collection of sample posts

Sample forum posts will be collected systematically from two cancer forums: Macmillan and CLIC Sargent. Macmillan is arguably the largest general cancer support network in the United Kingdom, with more than 15, 900 people visiting macmillan.org.uk each day (Macmillan, 2011). Likewise, CLIC Sargent is the largest childhood cancer network in the United Kingdom, providing support to patients and their families from diagnosis through to post-treatment. Both Macmillan and CLIC Sargent provide a variety of services, including nursing care, financial and practical assistance, information services, and welfare reform campaigns. The online communities of Macmillan and CLIC Sargent were chosen for analysis because of their high number of website activity, indicating that they are well-used by the cancer community. Also, Macmillan and CLIC Sargent are UK based and reflect the cancer experience of the general population of the UK (a self-imposed limitation of this study). Finally, their forums are open for the general population to read. Posts will be collected from various discussion groups within the online communities. Within the Macmillan site, posts will be gathered from the groups *children's cancers*, and *Parents of children with cancer.* After reviewing all of the posts on these threads, the search terms "child," "son," and "daughter" will be entered into the forum search bar, and posts from all of Macmillan's forums will be reviewed for inclusion. Only posts from the *For parents and family* discussion group will be collected from CLIC

Sargent. In order to be valid for analysis, posts must indicate that the poster is either a parent or carer of a child with cancer, and must have been posted within the past 12 months (from July 2011 onwards). A child with cancer will be defined as anyone with a tumour or blood cancer under the age of 15 (Cancer Research UK, 2010). Posts must indicate an information or support need in order to be included for analysis, but the need does not have to be posed as a question. Upon collection, any personal information that could potentially identify individuals included in posts (such as names and location) will be made anonymous, and a number will be assigned to identify the post during analysis. However, information regarding the poster's relationship to the child, what type and stage of cancer, and any demographics (such as income or education level) will be left in the post for analysis. All of the quotes taken from posts are verbatim, including grammatical and spelling mistakes. Unlike other ISB studies (such as Agosto and Hughes-Hassel, 2005), this study will only be looking at the identified information need, and will not be analysing what sources the user previously consulted.

3.2.2 Phase two: Identify information needs and code posts to appropriate categories

Initial coding will be conducted in parallel with collection of posts. Based on the literature review of the childhood cancer experience, six types of information needs have been identified prior to the collection of posts, including*: treatment information, disease information, impact on relationships, providing information to others, practical/daily life, and general social and emotional support*. Detailed explanations of the initial coding categories, including examples and corresponding literature, is provided below.

Treatment information: Any information need related to medication, procedures (surgical and non-surgical), alternative therapies, clinical trials, symptoms and side-effects of childhood cancer. As in the past decade there has been a shift to more out-patient care for children with cancer, parents have been called upon to provide treatments and recognize problematic symptoms (Kelly and Porock, 2005, pp. 59). Zwaanswijk et al, Norberg et al (2011), Pritchard et al (2010), and Poder et al (2010) have previously examined the treatment information needs of PCWC and indicated the high frequency of treatment information queries that exist among PCWC. Kelly and Porock's 2005 Delphi survey of pediatric oncology nurses found that "information about treatment was the most frequently cited priority" of information given during hospital care (Kelly and Porock, 2005, pp. 58). An example of a treatment information need includes: *What are the long-term effects of chemotherapy?*

Disease information: Information regarding the science behind the disease (see Szybowska et al, 2007). An example of a disease information need could be *What causes childhood cancer?* PCWC could seek to understand the science behind the disease in order to understand the childhood cancer experience and anticipate future cancer events, as well as to explain the disease to other people. Understanding the disease could also enable parents to be more proactive in the management of the care of their child. Sung et al (2009) and Rudolph et al (1981) have already provided examples of parents seeking disease related information during the childhood cancer experience.

Impact on relationships: As was shown in the background literature review (see section 1.3) the childhood cancer experience can have a significant impact on family relationships, including marital relationships, relationships between siblings, and the relationship between parents and the child with cancer. Da Silva et al (2010) focused their study on how communicating cancer information between parents affected the marital relationship. Other studies (Rodriguez et al, 2012, Mitchell et al, 2006, and Anderzén-Carlsson et al, 2010) have discussed the impact of the childhood cancer experience on relationships, as well as the correlation between healthy relationships and coping. An example of an impact on relationships information need might be expressed as *I can't seem to reach my husband; he won't talk about our child's cancer.*

Providing information to others: PCWC are not only called upon to make decisions regarding the care of their child, but also to act as information gatekeepers for others involved in the cancer experience, particularly the child (see Anderzén-Carlsson et al, 2010). The survey study of PCWC conducted by Mitchell et al (2006) indicated that an unmet information need was help in explaining the disease to others, including grandparents and the child's classmates (Mitchell et al, 2006, pp.

809). An example of providing information to others need might be *How do I tell my own mother about my daughter's treatment?*

Practical/daily life information: any information related to how to manage the daily family life of children with cancer. Information needs could include financial, conflicts between care management and other schedules (particularly work), taking care of other children's needs, and maintaining a household. Most of the literature regarding parental information needs mention practical/daily life information, including Kelly and Porock (2005) and Mitchell et al (2006). This information need also has a strong link to ELIS needs studied by Savolainen, and examines how information needs in daily life are affected by the cancer experience. One type of Practical/daily life information need might be *Do we qualify for any additional benefits because of my child's cancer?*

Social and Emotional Support: An expressed need for social (community) and/or emotional support during the cancer experience. As indicated by Sloper (2000), several studies have shown social support to have a significant positive correlation to parental coping. Likewise, it is anticipated from previous research into computer-mediated communication (see section 3.1) that PCWC will seek to gain and share information with individuals that have had similar experiences (see Rodgers and Chen, 2005). A type of social and emotional support need might be *My 22-month old baby was just diagnosed with bowel cancer. Has anyone had a similar experience?*

Following the methodology described by Agosto and Hughes-Hassel (2005) and Savolainen (2011), iterative pattern coding will also be employed during the collection of posts to expand and refine the coding categories. Iterative pattern coding consists of "repeated readings of the transcribed data, while searching for recognizable data patterns and tying pieces of data to deeper theoretical considerations" (Agosto and Hughes-Hassel, 2005, pp. 146). The iterative pattern coding process will identify specific information needs within categories that are repeated (such as information on specific procedures) as well as the possibly emergent new categories that have not been anticipated by the literature review. Coding will occur throughout collection and analysis of data. Because the literature review was based on findings from a medical perspective, it is fully anticipated that refinements to the proposed coding categories will occur.

3.2.3 Phase three: analysing posts for behaviours and preferences

Where available in individual posts, additional information provided by the poster will be analysed for characteristics of information behaviour. Additional information could include reported states of emotion, such as anxiety, or specific behaviours, such as secrecy. Because this is a historical research study, analysing information behaviour is highly subjective, and the data is being analysed retrospectively. Typically information seeking behaviour studies are conducted under observation. However, because one of the main purposes of this study is to analyse various causes of uncertainty in PCWC and how to avoid/reduce uncertainty, it has been deemed necessary to analyse posts for behaviours associated with established models of ISB. Precedence for this type of analysis has previously been established by Hassler and Ruthven's study (2011), as well as Savolainen (2011) (see section 3.1). It is important to note that identifying information needs within the posts is the primary objective of this study. Additional information behaviours will only be analysed where they are easily explicitly stated by the poster. It is hoped that this additional layer of analysis will provide insight into the information seeking experiences of PCWC, and will also be a valuable experience for the researcher in applying models of ISB.

The four models of ISB that have been described in the literature review (Chatman's information poverty, Savolainen's ELIS, Kuhlthau's information seeking process, and Wilson's model) have been chosen to analyse identifiable information behaviours from posts. Some anticipated behaviours to search for from each model include:

Kuhlthau's Information Seeking Process (ISP):

At what point in the cancer experience do PCWC search for various types (*support*, *treatment information*) of information? What events in the childhood cancer experience appear to initiate new information needs? What emotions do PCWC exhibit during information searches? Can the emotions exhibited be corresponded with the identified stages of ISP? "I am uncertain about 'x'" could be an indication of the ISP, and Kuhlthau's uncertainty principle.

Chatman’s Information Poverty:

Is the poster showing evidence of hiding information need from potential sources? For example, stating: “I can’t talk to ...about this.” Do they feel uncomfortable posing their question(s) to medical or information professionals? Have they been hiding or ignoring symptoms? Are they avoiding new information? Does the poster identify why they have chosen to post their information need anonymously online?

Wilson’s model:

What events are prompting information searches? Why are some sources of information used more than others? How do information searches affect coping and PCWC ability to manage care?

Savolainen’s ELIS:

Based on the analysis of the emerging coding categories, what type of information needs do posters identify? Are they looking for factual information, or opinions and experiences? How do PCWC make decisions based on the information they receive? Do they exhibit any problem-solving behaviour? What identifiable factors indicate how PCWC prefer to search and use information sources? (Case, 2007, pp 130). An example of ELIS could include: *I am seeking ‘x’ information to solve ‘y’ problem in our daily life.*

3.3 Presentation of findings

The findings from the study will be presented in section 4 of the dissertation report entitled “Findings and Analysis.” The presented information needs in collected posts will be quantified, in order to identify common needs and preferences, etc. Information behaviours from specific posts will be analysed qualitatively, in order to explore individual PCWC experiences.

Section 5 of the dissertation will include recommendations based on the analysis of data in section 4. The recommendations will specifically address how medical and support professionals can improve the information experience of PCWC and will refer to current initiatives. Recommendations for further study will also be addressed in section 5.

3.4 Methodology – Application Ethics

Ethics approval has been sought and granted from the department of computer and information studies ethics committee. As the use of archived forum posts is an emerging methodology, there are concerns between the boundaries of private and public information, and issues such as informed consent. The ethics application for this study was based on Eysenbach and Till's paper "Ethical issues in Qualitative Research on Internet Communities" (2001). This study is passive, with the researcher merely reporting and analysing previous posts, and not seeking additional information. As described in the methodology, all information that could possibly identify an individual will be made anonymous. The chosen forums to be monitored are open-access forums, which do not require registration to view posts, and are seen as 'public forums,' therefore not requiring informed consent. Likewise, the forums were chosen for their large number of participants, indicating that posts are not seen as private. Authors of posts will not be contacted, as this would be seen as an intrusion of their privacy.

3.5 Methodology – Anticipated conflicts

As was noted in section 3.1 (Methodology – Rationale) historical research of archived posts is not the ideal methodology to use regarding the initial research questions. Two main conflicts are anticipated, and will be accounted for during the analysis and recommendations for further research sections.

First, previous research (including Savolainen, 2011) indicates that users may present themselves differently online than they would in person. Likewise they might present different information needs online, or hide aspects of their information needs or behaviour. An extreme possibility is that posters might create fictitious stories or needs. Although the researcher is aware of this possibility, it is hoped that the process of categorization of posts will establish genuine patterns, and determine any 'outlying' information needs or behaviours, that will be discarded from analysis.

Second, the chosen methodology only offers snapshots of the childhood cancer experience, and does not follow individuals through the life course of the disease or throughout information searches (Rodgers and Chen, 2005). Hence, a full perspective of PCWC experience will not be gained. In addition, the postings are being analysed retrospectively, and do not specifically address the research questions. However, the researcher is aware of these conflicts and will attempt to keep analysis based on the information need presented, and any associated behaviours identified, and refrain from inferring meaning or feelings.

4. Findings and Analysis

4.1 Findings and Analysis – Introduction

As detailed in the methodology, posts were collected from the discussion forums hosted by Macmillan cancer support and CLIC Sargent. Collection of posts took place between 27 July and 10 August 2012, and spanned the period between July 2011 and July 2012. In total, 57 posts were identified for analysis based on the criteria defined in the methodology.

The analysis of the posts will initially present quantifiable measures, including the source of the posts, information needs described, and information behaviours that were identified. The analysis of the quantitative data will mainly focus on trends in how PCWC appear to use the forums (i.e. why they choose to post to certain threads), and highlight the common identifiable information needs. Following the discussion of quantitative measures, individual posts will be further analysed for qualitative data, and related to the ISB models discussed in the literature review.

Discussion of the findings will primarily focus on the preference PCWC exhibit for seeking and sharing information with other PCWC with similar experiences. The quantifiable evidence reflects how PCWC primarily seek to fulfil “emotional” information needs through online communities, rather than “factual” information needs. The application of the different ISB models will highlight evidence of information poverty, uncertainty, ELIS, and the relationship between information seeking and coping.

4.2 Presentation of quantifiable findings

Although several hundred posts were read, 57 were selected for analysis. The criteria for inclusion (see section 3.2.1) stated that the post had to be written by a parent or carer of a child with cancer (age 15 and under), and needed to define an information need, or describe an information behaviour. Many posts were excluded as they did not define a need or behaviour, but instead documented or described events.

The quantifiable data will be presented in two sections: post descriptors (what sites and threads the posts collected were found on) and categories of information needs. Discussion of each of the sections will highlight key trends, and refer to the literature review for possible reasons of occurrence.

4.2.1 Post descriptors

As posts were collected from two sources, Table 1 compares the number of posts collected from each site.

	CLIC Sargent	Macmillan Cancer Support
Total number of collected posts	23	34
Posts in child cancer specific threads	-	6
Posts in non-child cancer specific threads	-	28
Posts starting a discussion thread	10	17
Posts in response	13	17

Table 1

As can be seen from Table 1, most of the posts were collected from the Macmillan Cancer Support discussion forums. This can most likely be attributed to the fact that Macmillan's site has a higher number of visitors, and therefore generates more posts.

It is worth noting the difference between posts that were posted on childhood cancer specific threads (such as the group *children's cancers*) versus non-childhood cancer specific threads. Because CLIC Sargent is a childhood cancer specific organisation with only one discussion thread, the posts collected from their site were not relevant to analysis of thread source. However, Macmillan cancer support hosts a variety of discussion threads. The collected posts from Macmillan indicated that the majority of posts occurred *outside* of childhood cancer specific threads. Only roughly 18% of collected posts were posted on childhood cancer forums. While the remaining percentage of posts were found on a variety of forums, the most prevalent source for posts (especially posts that specifically addressed an information need) were cancer-type specific threads, such as kidney cancer, brain cancer, or leukaemia. These findings indicate that PCWC are typically more interested in disease-specific information, rather than the general experience of childhood cancer. One example of a post found in a non-childhood cancer specific thread is:

> "I am looking for somebody who has an experience with that type of cancer but really I am just looking to share some experience with anybody" (Post 75).

While the posts on non-childhood specific threads focus on specific disease-related experience, most of the posts analysed indicate that PCWC are still interested in finding other PCWC that have been diagnosed or undergone treatment with the same type of cancer as their own child.

> "How many chemos were given to your son few of my frinds say that number of chemo dose will differ dependong on the seriousness of ALL. Can you plz share some info and experience" (Post 39)

> "I would like to hear from anyone just to see if this is normal thing with this disease because i have read about some other kids with this who seem to be able to do more than she is" (Post 40)

> "I would like to make contact with other parents whose children have had this particular brain cancer" (Post 98).

These and similar posts indicate that while disease-specific information is important, it is also worthwhile for PCWC to communicate with each other about the experience of having a child experience the specific disease. It appears that PCWC seek to establish a community for information and support needs with other PCWC that are undergoing experiences most like their own.

Several other posts were found in various forums, such as *the new to the site* forum, as well as the *carers'* forum. Some of these posts, particularly those on the *new to* *the site* forum, indicated that they needed information or support, but didn't know where to post.

> "sorry if i have got the wrong blog just needed to tell someone as i cant find anyone that has went through the pain i have with losing a baby so young to cancer" (Post 18).

Posts in very general threads (including *general cancer discussions)* could indicate that a poster is new to the childhood cancer experience, and is in the initiation stages of the information search process as described by Kuhlthau (see section 2.1.1). Likewise, posts in general threads could indicate a degree of information poverty (discussed more in section 4.4.2), as PCWC express that they do not know who to ask for help, or where to post. One PCWC remarked on a general discussion thread: "Not sure where or if i shoild be posting here at the moment but I am looking for some advice and support or any feedback really for anyone that has been where my family is at the moment," (Post 37).

Analysing the discussion thread that a post was submitted in provides initial indications of what sort of information the PCWC is looking for, and can also highlight some information and coping behaviours that PCWC exhibit. The fact that PCWC appear to rate disease-specific information as more relevant while still seeking experiences from other PCWC could inform how discussion threads are organised, and even suggests the benefits of creating disease-specific childhood cancer threads (see section 5.4 in Conclusions and Recommendations).

4.2.2 Information Needs

As described in the methodology, the initial coding categories based on the literature review were: *treatment information*, *disease information*, *impact on relationships*, *providing information to others*, *practical/daily life information*, and *social/emotional support*. Using iterative pattern coding, an additional information need was identified as *similar experiences*. Although similar to *social/emotional support* needs, *similar experiences* specifically state that the poster is looking for other individuals that have undergone similar diagnosis, treatment, etc, that can offer advice or who have experienced similar feelings. Table 2 indicates the breakdown of identified information needs across the two website

	CLIC Sargent	Macmillan
Total number of identified information needs	19	44
Treatment information	3	5
Disease information	-	2
Practical/Daily Life information	1	3
Impact on relationships	-	7
Providing information to others	-	2
Social/emotional support	7	6
Similar experiences	8	19

Table 2

The data shows that Macmillan users' posts reflected higher numbers of stated information needs, as well as more of a variety of information needs. Again, this can probably be accounted for by the comparison of traffic each respective site receives, with Macmillan receiving substantially more visits than CLIC Sargent.

The least identified information needs were *providing information to others* and *disease information*, with only two posts. As is shown by the evidence provided in Table 2, by far the most sought information need was *similar experiences.* The prevalence of information needs is compared in Chart 1 below.

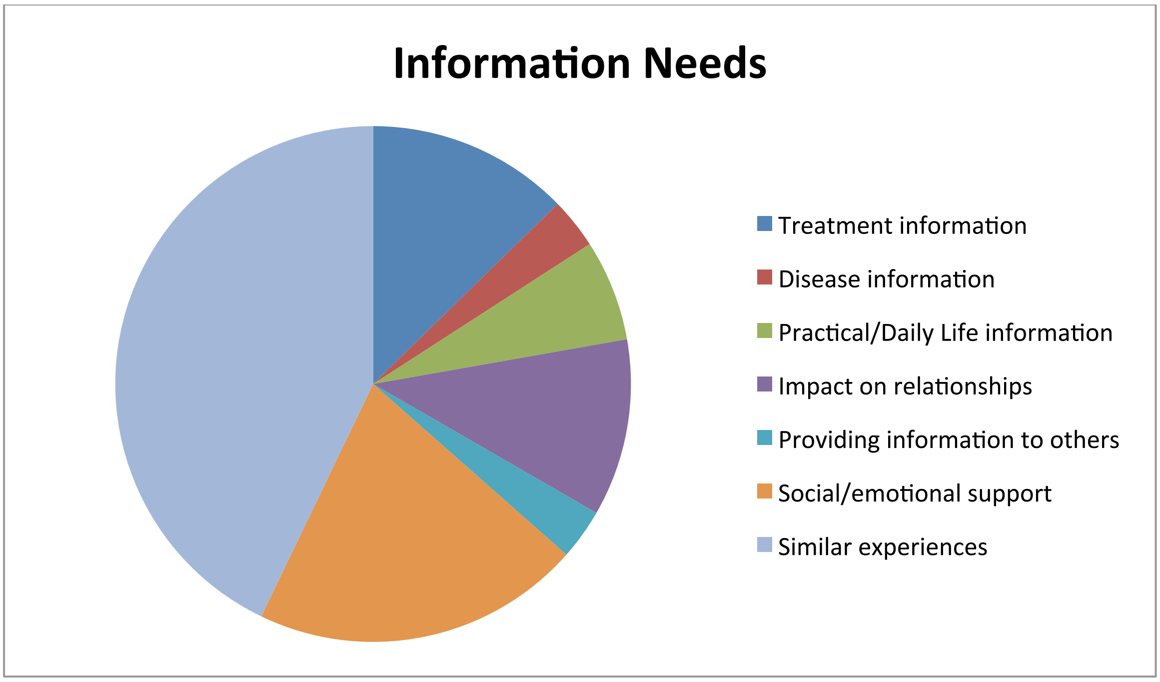


Chart 1

The methodology allowed for posts to be categorized in more than one category if appropriate. While there were 57 individual posts, some posts were included for analysis not because they identified an information need, but in order to analyse the information behaviour described within the post. Of the 57 individual posts, several posts identified more than one information need, and 63 information needs were identified total. For example, many of the posts that were looking for *treatment information*, *disease information,* or *providing information to others* were also included in *similar experiences* as they were specifically asking for experiences from other PCWC that have undergone the same procedures or diagnosis. An example of a post that was coded into two categories is:

> “This is the hardest thing for me because i don't whether he has the right to know,he is not a child but he is not an adult either [...] would love to hear from anyone about how and when they chose to tell their child the facts ?” (post 10).

The PCWC in post 10 described their situation of sharing with their adolescent child that he had been given a terminal diagnosis. In addition to asking other PCWC if as parents they should share this information with their child, the PCWC also specifically asks other PCWC to share their personal experiences with similar situations. Hence, post 10 was coded as identifying a need to know about *Providing information to others* (the ill child) and *Similar experiences*. The quantifiable findings below compare the number of posts with an identified information need, with the total number of posts.

Each of the information needs is discussed individually below. The discussion will compare the findings with the literature review, and discuss possible explanations for differences in expected results.

Treatment Information: With 8 out of the 57 posts chosen for inclusion in the study, the category of *treatment information* occurred in 14% of the reviewed posts. *Treatment information* had the third highest rate of occurrence, and posts from both CLIC Sargent and Macmillan identified *treatment information* as a need.

Although *treatment information* received the third highest rate of occurrence, the occurrence rate was unexpectedly low, based on the reviewed literature. Several of the reviewed articles on PCWC information experiences indicated that *treatment information* was one of (if not the most) sought after information need. In addition to their own findings through their Delphi survey of pediatric oncology nurses, Kelly and Porock‘s (2011) literature review also "consistently identified information about the child's disease,treatment, and side effects of treatment as priority educational needs" (Kelly and Porock, 2005, pp. 59).

The fact that PCWC aren't identifying *treatment information* as an information need in their online posts could have two explanations based on the literature. First, PCWC might be receiving *treatment information* from other sources (most likely medical professionals) and are adequately satisfied with the information they receive, and therefore do not seek further information elsewhere. Mitchell, Clark, and Sloper's (2006) findings of PCWC high-satisfaction rates with "treatment explanations" given by medical professionals provides evidence to support this theory. Second, the reviewed literature stated actively searching for and applying information as an indication of PCWC coping skills (see Maurice-Stam et al, 2008, Norberg, Poden, and von Essen, 2011, and Hardy et al, 1994). The lack of posts indicating PCWC searching for additional treatment information could indicate PCWC are not coping with their child's diagnosis. However, as this study does not follow individual PCWC, it is difficult to ascertain if they are searching for treatment information elsewhere, as online forums are not a preferred source.

Disease information: Only 2 of the 57 reviewed posts indicated a need for *disease information*. The definition of *disease information* being closely related to *treatment information*, it is again surprising that the occurrence rate is so low, based on the literature review, which indicated *disease information* as a high concern for PCWC. Again, this might be accounted for by the fact that PCWC are satisfied with the *disease information* that they have received from other sources, or are choosing to not to search for *disease information* on discussion forums, or from other PCWC. The two posts that were categorized as identifying a *disease information* need did indicate that they were confused by conflicting information that had been provided to them previously.

> "Has anyone heard of RGNT ? Or rosette forming glioneuronal tumour of the fourth ventricle ? [...]I was told he would not be able to be operated on again and radiotherapy was not advised And I find out now he has to have a big op again and then radiotherapy after so I'm petrified now As after 5 years of fighting it seems the worst is yet to come" (post 35).

The PCWC in post 35 indicates that s/he was originally given one prognosis and description of treatment, but that treatment has subsequently been changed. It appears that this change in information has caused uncertainty over information and advice given, and even after 5 years of the PCWC undergoing the childhood cancer experience, the PCWC in post 35 is still seeking information regarding the disease. While information seeking experiences, and particularly the ISP described by Kuhlthau, are a cyclical process, post 35 shows a re-manifestation of uncertainty in advanced stages of information seeking, when the user should be able to manage uncertainty.

The other post identifying *disease information* as a need further indicates that satisfaction with *disease information* is directly related to the experience of receiving the information (i.e. perceived quality/ validity) as well as the information literacy skills of the PCWC. Post 71 is written by a woman seeking information on behalf of a young, single mother. The poster states:

> "I am the friend of a young woman xx whos five year old son was diagnosed on xx, with Diffuse Pontine Glioma. I have been trying to help her gather information so we can learn more about this terrible disease and what is in store for her and her wonderful son. we were told that the tumor may be liquefying. I am wondering if this is something that is common with this type

> of tumor? Is this good news? Is is probable that the tumor will return?" (Post 71)

Later posts in this discussion thread indicate that the mother of the child is struggling significantly financially, and with her ability to manage the care of her son. It is worth questioning whether her ability to search for and use information is the cause of her reported inability to cope with the situation, or if the inability to search for and understand information is a symptom of her coping skills. Regardless, the low number of posts indicates that in general PCWC do no seek *disease information* from other PCWC on discussion forums. However, the limitations of this study do not allow for a judgment to be made of if *disease information* is not sought in general, or if PCWC are seeking it from another source.

Practical/Daily life information: With one of the lowest rates of occurrence, *practical/daily life information* was only reflected in 4 of the 57 posts. This finding is very surprising, as the literature inferred that typically medical and treatment information was sought from medical professionals, while other information, such as coping in daily life and at home, would be sought through other non-medical channels – such as online discussion forums and from other PCWC (see Kelly and Porock, 2005, Mitchell et al, 2006, and Rodgers and Chen, 2005). Likewise, Savolainen's model indicates that ELIS continues to exist, although it is affected by the cancer experience. However, the posts gathered in this study indicate that *practical/daily life information* is not a reported significant information concern to PCWC.

A reason for the low occurrence rate of *practical/daily life information* might be that the methodology was too strict in the definition of the information need. The methodology stated that the need would be defined as "how to manage the daily family life of children with cancer." Many of the posts related experiences of home-life with the disease, but did not state an information need of how to manage/improve home and daily life. Most of these posts reflected symptoms of the child (such as lethargy or apathy), and the information need identified were more towards the disease symptom, not the fact that the need was occurring at home or affecting daily life. An example is:

> "The worst thing for me is that she seems totally depressed and does not want to do anything except watch tv no amount of coaxing will move her.

> Occassionaly she has played a bit with her big sister but this has been very far and few between” (post 40).

If the methodology was expanded to include any situation that occurred in a home environment, the incident rate of *practical/daily life* would increase significantly. However, as the need is partially defined as “management” of home life (not symptoms) the majority of these posts are currently excluded.

Impact on relationships: With only seven posts stating *impact on relationships* as an information need, or as affecting other information needs, this category was also surprisingly low based on the reviewed literature. The literature indicated the childhood cancer experience affects the entire family, particularly the marital relationship, and was a measure of PCWC coping (see Da silva et al, 2010, and Rodriguez et al, 2012). However, similar to *practical/daily life* information needs, only a relatively small portion of posts reflected information needs not strictly related to symptom management.

All of the posts that were identified as having *impact on relationships* needs did not state that the *relationship need* was the primary need, but rather was caused by other needs (typically treatment) or that negative impact on a relationship was having an influence on gaining other types of information or coping skills in general. Hence, PCWC did not appear to be actively seeking information on how to improve or manage relationships during the cancer experience. For example:

> “I on the other hand feel like the most isolated person in the world!My friends and family hardly speak to me and i can only asume its because they dont know what to say and they will never undertand. Ive never felt so low and alone in my entire life. But my daugter is my little star she keep me going every single day” (post 43).

> “We are lucky to have good support from friends and family, although many friends don't know that [her] condition is terminal. I can't really truly confide in many - my husband really, and then to everyone else I suppose I just put on a brave face and carry on as best I can” (post 3).

Post 3 reflects how the childhood cancer experience has isolated the PCWC from friends and family. However, the PCWC does not specifically state that she is searching for information to improve her relationship with others, but merely accepts it as a part of the childhood cancer experience. She goes on to say that “putting on a brave face” helps her achieve a “sense of normality” (post 3). Although the PCWC in post 3 has indicated that her daughter's condition is terminal, and therefore they are in the final stages of the childhood cancer experience, other posts do not state at what point in the childhood cancer experience they are experience *impact on relationships* needs. Therefore, it is difficult to ascertain if *impact on relationships* is more of an information priority at earlier stages of the childhood cancer experience.

Some of the posts also indicated how *impact on relationships* was affecting other information needs – such as *treatment information*, or *providing information to others*. One father who is separated from his child's mother describes:

> "The doctors will say my daughter is doing well, progressing (when they can be arsed to speak to me) whilst the mother will only send negative thoughts...hard to know what's going on" (post 79).

Post 79 conveys that relationships, particularly marital relationships, can affect how information is shared between PCWC during the childhood cancer experience. This finding is further confirmed by Kelly and Ganong's (2011) study on the childhood cancer experience of single-parent and re-structured families and on how family structures are altered by the cancer experience of the family, particularly related to treatment-decision making (TDM) roles. While the literature review emphasized the impact of the childhood cancer experience on family (particularly marital) relationships, the posts collected during this study indicate that investigating how family structures and relationships influence information needs and behaviours would be a useful area of future study.

Providing information to others: Only 2 of the 57 gathered posts indicated an information need of how to provide information to others. The posts were actually related, as they were posted by the same PCWC, and discussing similar events with the same child. Post 10, which is described above (see page 33), indicated that the PCWC was seeking information of how to share treatment/diagnosis information with their ill child. Post 11, which is contained in the same discussion thread, states a similar need:

> "It just seems so hard to talk to people when they ask about [him] because i can't tell them everything for fear of [him] hearing the facts from someone else.Sometimes i just think that it would be easier for everyone to talk if things were out in the open" (post 11).

Different from post 10, post 11 indicates that the PCWC is looking for how to best share information with other people, while maintaining the relationship with her son, and not causing him undue stress.

Other posts included PCWC sharing their frustration when other individuals misjudged their child without knowing the history of their illness:

> “The odd thing about it is, whilst I don't want people to pity him, the fact that he never went bald means there was no 'visual' to his illness and especially at times of steriods when they are very out of character, you just want to scream 'he's sick!!!'” (post 55).

However, these posts merely reflected their experience of encountering individuals that are not familiar with the childhood cancer experience. The PCWC of these posts did not indicate that they had a need to know how to share information with other people.

The low number of PCWC indicating that *sharing information with others* was an information need could indicate that Mitchell et al (2006) overestimated the significance of helping PCWC explain their child’s disease to others. However, additional studies (Anderzén-Carlsson et al, 2010, Young et al, 2002, Zwaanswijk et al, 2011) have also briefly examined the role of PCWC as information gatekeepers for their ill child as part of other studies. While the posts collected in this study do not reflect the experience of PCWC sharing information with their child and acting as gatekeepers, if PCWC are questioned or surveyed specifically regarding the experience of sharing information with their ill child, responses might indicate a higher prevalence of *providing information to others* as an information need.

Social/emotional support:

The most difficult information need to objectively categorize was *social/emotional support*. It can be assumed from the general childhood cancer experience and from the gathered posts describing experiences and feelings that most PCWC have some form of *social/emotional support need*. However, most PCWC do not specifically ask for advice or help to fill their need. While it could be inferred that many, if not all, of the posts chosen for inclusion could also be classified as having a *social/emotional support need*, posts were only included in this category if the PCWC specifically sought information/help, or it was clearly evident that the *social/emotional support* *need* was significantly impacting on their daily life, or the ability to manage the care of their child. One such post comes from a PCWC that is struggling with their child's recent diagnosis:

> "Still shocked and horrified ... I can`t begin to explain my despair ... Haven`t stopped crying (post 42).

Because the PCWC describes herself as being "shocked and horrified" as well as "haven't stopped crying," this post was included in the category *support/emotional needs* as these emotions indicate an inability to cope with the situation (da Silva et al, 2010). Post 42 highlights how many PCWC are able to express their emotional state and symptoms of their coping, but they are not able to express an information or support need.

Of the posts that did specifically address a *social/emotional support need*, many PCWC described their experiences seeking counselling in order to cope with the childhood cancer experience. One PCWC relates:

> "I spoke to my gp briefly who said its quite likey that im a bit depressed and suggested counciling but the idea of talking to someone who has no idea this feels will not be very helpful!!" (post 21).

Along a similar line, another PCWC posted:

> "I think the best people to talk to are those who have been through similar, I was offered counselling in my home town but when I asked if they had been through this themselves or delt with it before they had not, so i declined the offer I speak instead to a lady in the next village whos son has been through this awful illness and it helps us both greatly" (post 44).

Posts 21 and 44 represent several *support/information need* posts that indicate that PCWC have a preference for receiving *support/information need* information and advice from other PCWC or individuals that have a deep understanding of the childhood cancer experience. This finding could be evidence of information poverty (discussed more in section 4.4.2) and PCWC forming a group of insiders/outsiders, as well as having aspects of secrecy and deception. Regardless, this preference for information from other PCWC should be taken into consideration by medical and cancer support professionals offering help to PCWC. This finding is in line with Rodgers and Chen's study (2005), which suggested that individuals seeking medical support information (particularly in online communities) prefer to receive information from other individuals who have undergone similar experiences.

Similar experiences:

With 27 of the 57 collected posts, the largest reported information need of PCWC was *similar experiences*. Although not one of the original coding categories, it soon became evident that *similar experiences* had enough respondents reporting a need that it deserved a separate category from *support/emotional needs*. Likewise, PCWC express a need to communicate with others with *similar experiences* over non-emotional needs, such as treatment information. As was discussed in the findings of *support/emotional needs* it is evident that PCWC typically post on online forums in order to receive information from individuals who have undergone similar experiences. The significance of having a personal understanding of the childhood cancer experience is expressed in posts such as:

> "it's easy to tell anyone that your child has cancer,but it's so hard to spread about how you feel inside,unless that person has experienced it" (post 26).
>
> "I have lots of supportive family and friends but they do not know what I am facing.I would love to hear from anyone who can understand what I am going through and who have faced this pain themselves." (post 27).
>
> "i am trying to find families that have experienced this type of cancer and have got through it because at the monet my wife and I are soo scared we need some hope etc" (post 49).

The need to communicate with others over *similar experiences* could be considered an information preference rather than a need; *similar experiences* often implies there is no specific query or question to be answered, but rather just reassurance that others have experienced similar circumstances and events. While not strictly an *information* need, sharing *similar experiences* can fulfil an emotional need to relate to one another, and helps build trust and establish empathy – which leads to successfully fulfilling other information needs. While some PCWC do seek information in order to anticipate future events, some just want to know they are not alone. However, the need to establish a community and support channels can be considered an information need, particularly as it has a significant connection with coping behaviour (see Norberg, Lindblad, and Boman, 2004 and Rodgers and Chen, 2005). Furthermore, seeking other individuals with *similar experiences* could be an example of Dervin's Sense-Making theory (see section 2.1) as PCWC rely on others to help them make sense of their situation, and move from uncertainty to understanding.

Similar experiences as an information need is difficult for medical and support professionals to fulfil, as it is dependent on the information provider having undergone the same experience. Most of the research conducted on information experiences of PCWC has neglected to study the importance of *similar experiences* and encouraging support networks for PCWC, but rather focuses on how disease and treatment information is shared with the family by medical professionals (Maurice-Stam et al, 2008, Zwaanswijk et al, 2011, Mitchell, Clarke and Sloper, 2006, Norberg, Poder, and von Essen, 2011). While some of the general literature on computer-mediated information sharing and information-seeking investigated the community aspect of sharing information (see Rodgers and Chen, 2005, and Savolainen, 2011), the childhood cancer-specific literature neglected to investigate the impact of PCWC sharing information with each other and encouraging interaction among PCWC in various settings (in hospital, in the general community, and online).

4.3 Discussion of information needs

As was shown by chart 2 and the discussion of the individual information need categories, it appears that the most often sought information by PCWC is *social/emotional support* and *similar experiences*. Several of the posts that were reviewed did not seek information, but simply wanted to share experiences, or memorialize a lost child.

> "My little boy, xx, aged 8 died from a brain tumour 2 years ago. He fought it bravely with determination for 11 months. It has left a huge hole in my life. I miss him and love him more every day. Life will never be the same again but with the support of my partner and my mum I am slowly rebuilding my life" (post 15).

Posts like post 15 may not include an information need, but indicate that even PCWC without an information gap still desire to communicate with other PCWC. 57 posts were included for analysis, while only 45 stated an identifiable information need. Many of the posters not looking to fill an information need emphasized their need to "share" information, or to "report" on their situation.

Even when PCWC seek treatment and disease information, it is to compare with other PCWC experiences and perspective, not to gain a better understanding of the disease itself or a medical explanation. This finding could be a reflection of the methodology, as PCWC weren’t questioned directly about their information needs or asked to rank the importance of their needs. Likewise, the findings and high incidence of “emotional” information needs, not “factual” information needs, was probably influenced by the design of this study collecting data from forums dedicated to individuals undergoing the cancer experience interacting with each other, and may not reflect information that PCWC would seek from a medical professional. The low response of *practical/daily life* needs could be accounted for by the fact that neither Macmillan or CLIC Sargent have forums dedicated to *practical/daily life* needs of PCWC, and parents are unsure about where to report such needs. The design of this study has left unanswered if PCWC have medical related information needs that aren’t being met by medical professionals, or their preferences for receiving medical related information. Likewise, this study does not include a measure of demographics for the individuals seeking information. Therefore it is difficult to ascertain what factors (income, education level, age, marital status) influence information needs and behaviours.

However, this study has shown the importance of PCWC interaction, especially the need of PCWC to form relationships with others that have undergone experiences as close to their own as possible. The analysis of online forums does indicate PCWC are undergoing Sense-Making (see section 2.1) by choosing to communicate with each other, in order to better “make sense” of their experience, for both practical and emotional support. For example, post 7 states, “Is there anyone out there in a similar position? Or any ideas about how to cope?” The PCWC in post 7 is actively trying to make sense of her situation (or “cope”) and shows a preference for receiving information from other PCWC. As it appears to be a general information preference for PCWC to communicate with each other, systems and information providers should make efforts to create and encourage communities for PCWC to share experiences with each other.

4.4 Qualitative information: investigating information behaviours

The quantitative information provided in section 4.2 gave some indications of patterns/trends of information needs among PCWC, and generalised the childhood cancer experience of PCWC. The qualitative information below is not meant to provide an indication of patterns, but to explore individual PCWC information experiences, provided by the first-hand accounts of their posts. Gorman and Clayton (2011) define qualitative research as:

> "a process of enquiry that draws data from the context in which events occur, in an attempt to describe these occurrences, as a means of determining the process in which events are embedded and perspectives of those participating in the events, using induction to derive possible explanations based on observed phenomena" (Gorman and Clayton, 2011, pp. 3)

While the best method of collecting qualitative data is typically by observation, such as the various studies conducted by Chatman, the methodology of this study does allow for some qualitative analysis because the PCWC are providing first-hand accounts of their situations. An acknowledged limitation of this study is that the qualitative analysis relies heavily on the investigator's personal (potentially subjective) interpretation of the information provided. Therefore, causes of information behaviour will not be analysed. Each of the information behaviours provided in the literature review will be discussed, with posts that include observable information behaviours. The presentation of posts is merely meant to show how the reviewed ISB models can be applied to PCWC experiences, and recommend areas of further investigation.

4.4.1Application of Kuhlthau's Information Seeking Process (ISP)

Because this study only examines individual online posts from PCWC and does not follow individuals throughout the childhood cancer experience, it is difficult to apply Kuhtlhau's ISP model and study the various stages of information seeking of PCWC. However, some PCWC did give indications of what stage of the childhood cancer experience they were undertaking while describing their information need in their post – such as diagnosis, or treatment, or bereavement. Kuhlthau's stages are also identified by four aspects of behaviour: affective (emotional), cognitive (what are the searches trying to accomplish?), and actions and strategies (what are searchers doing to achieve their goals?). Many PCWC included descriptions of their emotions during the search process, accounting for Kuhlthau's affective aspect of ISP. It appears that PCWC associate their emotional and information needs particularly at diagnosis and early treatment, and during bereavement – the stages of cancer where they are not actively pursuing treatment or cure, and hence they have limited actions and strategies. Some examples of PCWC at early treatment include:

> “...diagnosed with a brain stem tumour almost 4 weeks ago. The hardest thing i am finding just now is the not knowing” (post 12).
>
> “...diagnosed with this rare type of brain tumour a month ago...we are totally devastated by the news but are somehow managing to take each day as it comes.it is so hard coping with all the uncertainty first of all about whether the treatment will work (we were told about 50/50 chance) and then about all the after effects of treatment” (post 30).

The PCWC in post 12 and post 30 have only recently started the childhood cancer experience, and are presumably in what Kuhlthau would term the “initiation phase” of information seeking (Kuhlthau, 1991, pp. 366). The posts indicate that the PCWC perceive they have an information need, but have not yet established how to fill that need. Their actions indicate that they are talking with others and browsing for information. Although they recognise that they have uncertainty, they are tolerating their uncertainty by not allowing it to diminish their information seeking capacity (Kuhlthau, 1991, pp. 366).

Likewise, two PCWC undergoing bereavement or entering palliative care related:

> “I think my brain is still trying to protect me with that numbing sensation as there is something so surreal about all of this...how can I be childless in just 5 months??? it makes no sense. When they do know , I'm first in that queue for the answers please!!!” (post 73).
>
> “I just cried and cried. To be honest, in between doing my best to act like everything is ok around the kids, that's pretty much all I've been doing since. My partner [...] has been tirelessly researching. Seeking second opinions, looking at new treatments. [My child] is basically receiving palliative care now. I'm so profoundly sad I can't even find the words to express it” (post 51).

While the PCWC in posts 73 and 51 have reached the final stages of their childhood cancer experience, it appears that they have returned to the early phases of ISP. Their posts are marked by uncertainty, and extreme depressed emotions and apprehension. It can be assumed from the information given in posts 73 and 51 that the PCWC have developed new information needs that focus on how to deal with the loss of a child, instead of how to manage the care of an ill child. Therefore, although the experience of actively managing the care of their child is drawing to an end, they have returned to the “initiation” phase of ISP, as they begin to search for sources and strategies to fulfil their new information needs.

As was discussed in the literature review, uncertainty pervades the childhood cancer experience both in terms of information seeking, and uncertainty over the progression of the illness. The posts collected during this study confirmed the existence of uncertainty pervading the childhood cancer experience. Although Kuhlthau's ISP model emphasises the goal of moving from uncertainty to understanding, it appears that most PCWC never truly reach this goal. Several PCWC who had completed treatment remarked sentiments of "what if it comes back?" (post 13 and post 21).

While many PCWC reported experiencing uncertainty, very few offered explanations of how they managed their uncertainty. Those that did discuss how they managed uncertainty mentioned conducting their own research into alternative therapies (post 53), *not* seeking additional information (post 74), and seeking counselling services. Some PCWC specifically mentioned using CLIC Sargent nurses to aid them during the cancer experience (including post 3 and post 44). The fact that the PCWC are posting to a discussion forum for support can also be seen as a way to manage uncertainty over information and the childhood cancer experience. As was shown in the discussion of information needs, the primary reason PCWC posted to the discussion forums was to interact with other PCWC that had undergone similar experiences. Seeking advice and information from others can be seen as actively engaging with the information need, and therefore seeking understanding.

4.4.2 Application of Chatman's Information Poverty

As was discussed in the literature review, Chatman identifies information poverty as individuals or communities that not only have information needs, but also lack the resources or skills to fulfil their information needs. Chatman's six propositions discuss how the information poor employ self-protecting behaviours caused by mistrust, see themselves devoid of resources, and introduce new knowledge selectively.

One post, by a young PCWC who lost a newborn baby to cancer, depicts some of Chatman's propositions. After visiting several medical professionals regarding the child's poor condition, and getting conflicting information, the PCWC describes:

"noone could help me[...] told me it was her milk or that i was just being paranoid witch was understandable at the point[...]i started to panic and noone would listen" (post 18).

The PCWC in post 18 describes several times that she didn’t know where to seek information, and felt that when she did ask for help, she was ignored by medical professionals, or given incorrect information – which led to mistrust. It is also evident that the PCWC felt isolated – “no one could help me.” Considering the number of times the PCWC describes seeking medical help for her newborn without satisfaction, it could be considered “a risk” that she continued to seek help, and did so based on her perception of the situational relevance of new information for the care of her child. Likewise, when the PCWC did receive a reliable diagnosis, she relates “i knew it was real just didnt want to belive it” (post 18) and taking time to accept the diagnosis – which could be interpreted as a sign of selectively introducing new information.

Other PCWC display similar attributes of information poverty, particularly confusion over receiving conflicting information, or feeling as if their information needs are not being met or listened to. Another PCWC describes their experience of having their child diagnosed:

> “We too went through the torment of guilt at not knowing that the swelling in her cheek was cancer. After an accident at school, we took her to the GP, to A & E, back to the GP, back to the local hospital to see a Peadiatrician and all the time we were fobbed off until I spotted the lump in her gum” (post 25).

These posts described by PCWC of feeling devoid of sources, and receiving poor information, indicate how unsuccessful information events can have a significant negative impact on the PCWC to seek and use information effectively in the future, as well as on their psychological/emotional state. The impact of feeling marginalised appears particularly significant early in the childhood cancer experience, while the PCWC is in the early stages of receiving/gathering information

4.4.3 Application of Wilson’s model

Wilson’s model examines how information seeking is influenced by several factors, including the socio-demographic background of the searcher, and the searcher’s confidence in information seeking. While Wilson’s model draws on several sociological theories and raises several questions regarding what influences the information seeking process of individuals, the literature review proposed a few questions that could be applied to the study of PCWC:

- Why some cancer events (diagnosis, new symptoms, treatment) prompt information seeking more so than others?
- Why do PCWC prefer some sources of information? Why are medical professional relied upon for non-medical information?
- Why do PCWC choose to, or not to, be actively in charge of their child's care, based on their perceptions of their own efficacy?

Based on the design of this study and on the experiences presented in the collected posts for this study, the only question that could be reasonably discussed is "why some cancer events (diagnosis, new symptoms, treatment) prompt information seeking more so than others?" It appears from the collected posts that PCWC seek information most actively at diagnosis, and when the prognosis of the cancer changes dramatically and new information needs are presented. Wilson's analysis of what prompts information searches is primarily based on the stress/coping theory from the field of psychology. Some of the collected posts support Wilson's view of information seeking as a source of coping:

> "I looked at lots of complementary treatments for him to supplement his chemo and radiotherapy. The doctors werent keen for me to do this, but I have used different therapies for years and they have been amazing[...]. Please keep positive [...] you will be amazed what might leap out at you when researching" (post 53).

Wilson's model also questions why some sources are preferred over others. As has been presented throughout the findings and analysis, it appears that PCWC have a preference of receiving emotional/support information from other PCWC. Wilson's application of risk/reward theory could explain this preference. PCWC risk very little by exposing their needs to other PCWC (as opposed to medical professionals), however they are rewarded with personal experiences similar to their own, and often genuine empathy from other individuals.

> "I know what you mean about wishing you'd found out earlier, but at the same time wish you still had life as normal. Ignorance was bliss but didn't know it at the time and now feels like a never ending nightmare with nothing good on the horizon" (post 64).
>
> "The not knowing is awful,i know [...]I know exactly how you feel so if you ever need a chat im here" (post 66).

While Wilson's model makes active use of theories from various disciplines that could be useful to the study of PCWC ISB, it is a very complicated model, and difficult to apply during this retrospective study. As PCWC coping behaviour is a large area of research within childhood cancer support studies, a future study might employ Wilson's model to investigate specifically at how PCWC coping behaviour and information seeking behaviour are related.

4.4.4 Application of Savolainen's ELIS

Savolainen's ELIS model is focused on studying individuals' "non-work" activities. However, Savolainen shows that "working and non-working information seeking are not exclusive of one another, but rather are often complementary" (Case, 2007, pp. 130). The distinction between "work" and "non-work" life often becomes blurred during the childhood cancer experience, as managing the care of an ill child often becomes a full-time requirement, with all family time and resources focused on the child's treatment. One PCWC remarked: "Just seems to be a minefield of information about drugs, living arrangements etc . It's surely a full time job and some ?!" (post 4). It appears from many of the collected posts that the childhood cancer experience often *becomes* PCWC's occupation, and their life world.

One surprising result from this study was that PCWC had a low rate of seeking *practical/daily life* information – what would typically be considered ELIS needs. As was shown in Table 2, only 4 of the 57 collected posts specifically identified a *practical daily life* information need. However, many of the collected posts emphasized that PCWC seek various types of information to manage the disease, in order to maintain stability and normality in other areas of family life.

> "I wish my outside life could just go on hold until we get through this. My daughter was readmitted this eve with a temp of 40.5. She has only managed 2 days at home. I have 3 other children to juggle and it does feel impossible at times" (post 47).
>
> "My husband is now off work, and it takes both of us and more to keep things on a even keel here" (post 20).

This desire to manage home life and keep an "even keel" (post 20) could be an example of Savolainen's use of "mastery of life" or individuals' attempts at "keeping things in order." Savolainen breaks down "mastery of life" into two main areas: "type of mastery of life" and "problem solving behaviour." "Type of mastery of life" can be compared to PCWC emotional/psychological state, and includes: optimistic-cognitive, pessimistic-cognitive, defensive-affective, and pessimistic-affective cognitive styles. Similarly, "problem solving behaviour" can be linked to how PCWC manage the care of their child – whether they take an active role in care management, how they seek and use information, how they evaluate situations, etc. Savolainen goes on to show how maintaining a "mastery of life" is affected by several factors (such as unanticipated events and daily life events), as well as values, material capital, social capital, cultural and cognitive capital, and the individual's current state of health.

Overall, even though *practical/daily life* information needs had a low rate of occurrence, Savolainen's model can be applied to how PCWC seek information in order to maintain their everyday family life, and to study the coping ability of PCWC.

4.5 Findings and Analysis – Conclusion

The findings of this study highlighted that PCWC show a preference for receiving information from other PCWC; particularly *social/emotional* support information. While the literature review anticipated PCWC to seek *practical/daily life information* and how to *provide information to others*, the posts collected for this study did not show *practical/daily life information* and *providing information to others* as priorities among PCWC seeking information on discussion forums. The collected posts also indicated that receiving conflicting information, or unexpected disease events, has a significant effect on the information seeking experience and ability of PCWC. The application of the reviewed models of ISB further emphasized the link established in the literature review of coping behaviour and successful information seeking. The recommendations will build on these findings, and suggest future research, as well as ways medical and support professionals can increase PCWC contact, and improve PCWC information seeking experiences.

5. Conclusions and Recommendations

5.1 Conclusions and Recommendations – Introduction

The conclusions and recommendations will focus on the primary finding from the study that PCWC show a preference for receiving information and sharing experiences with other PCWC; hence, the primary recommendation for services is establishing cancer type-specific forums for PCWC to converse with each other. The first section will review some of the major findings from the study and address what questions were raised or insufficiently addressed by the study. Recommendations for future research, specifically ISB studies, will be presented. Service recommendations for medical professionals and support services will also be proposed, and will address previous literature and the initiatives presented in the introduction.

5.2 Review of findings from the study

The major finding from this study was the high incidence of PCWC (27 of the 57 analysed posts) seeking other PCWC with similar experiences, indicating that PCWC have a preference and an emotional need to receive and share information with other PCWC that have undergone experiences close to their own. However, the rate of PCWC seeking *treatment information*, *disease information*, or *practical/daily life* information was surprisingly low. The reviewed literature, primarily from a medical professional perspective, indicated that *treatment information* was the most commonly sought information need among PCWC. Especially as the treatment of childhood cancer is turning towards more out-patient and home-based care, medical staff report that the primary information need they address from PCWC is how to administer treatments at home, and symptom management (see Kelly and Porock, 2005). This study was not able to address if PCWC do not typically identify *treatment, disease,* or *practical/daily life* information types as needs and that medical staff have previously overestimated the occurrence of these information needs, or whether they seek these types of information from sources other than online discussion forums, and hence weren't accounted for in this study.

An analysis of the thread source of individual posts indicated that while most PCWC are seeking information from PCWC, most of the posts occurred on general or disease-specific discussion threads – not on childhood cancer discussion threads. Several of the reviewed posts on general discussion threads indicated a degree of information poverty, as PCWC stated specifically that they wanted to find other PCWC to converse with, but were unsure of where to look for other PCWC with similar experiences.

This study also identified that significant events in the childhood cancer experience (new diagnosis, new symptoms, and palliative care) increased uncertainty in PCWC and identified new information needs. But, the methodology prohibited studying how information needs and use change throughout the childhood cancer experience, and instead focused on isolated events. The Leydon et al (2000) study indicated that among adult cancer patients, the rate of information seeking is highest at diagnosis, and nearly completely diminishes during the final stages of cancer care – particularly if the patient enters palliative care. The design of this study prevented studying the rate of information seeking throughout the childhood cancer experience, or even a full range of information needs of PCWC and the variety of sources they employ. The gathered posts merely indicated that a change in the childhood cancer experience prompted PCWC to seek information and support on online discussion forums. This finding is corroborated by the reviewed ISB models, which all indicate that new events can increase uncertainty and initiate a new information search.

Although not the primary intent of this study, several of the gathered posts were analysed according to the reviewed ISB models. The application of Kuhlthau's ISP showed that PCWC exhibit emotions (affective behaviour) during the early and late stages of childhood cancer, when they are not engaged in actively fighting the cancer. Kuhlthau's ISP also showed how significant events (particularly bereavement) could initiate a new ISP. A review of Chatman's Information Poverty indicated that information poverty does exist among some PCWC – particularly when PCWC receive conflicting information and are unsure of where to find answers, or consider themselves marginalised. Further study of PCWC information poverty would need to examine in-depth the life-world of PCWC and their background demographics, as this study did not have access to that information. Wilson's model again showed how certain events in the childhood cancer experiences (new diagnosis, new symptoms, palliative care) initiated new information needs. Wilson's model was also applied to indicate that PCWC seek information from other PCWC because of the risk/reward theory – it is a low risk and possibly a high reward to seek information from other PCWC who understand their situation. Finally, applying Savolainen's ELIS model indicated that the childhood cancer experience often *becomes* PCWC occupation and life world. Surprisingly, the incidence of *practical/daily life* information needs was low throughout this study. However, the application of Savolainen's model to specific discussion posts indicated how PCWC attempt to achieve a "mastery of life" by maintaining everyday family life throughout the childhood cancer experience.

5.2.1 Limitations of study

As was addressed in the methodology (see section 3.5) this investigation was not designed to be an exhaustive study of PCWC information needs and behaviours. Several limitations were implicit in the methodology. Foremost, the methodology of reviewing archived discussion threads heavily relied on the researcher's interpretation of the information and was highly subjective. PCWC were not responding to specific questions, and any patterns and findings identified in the data could arguably be biased to the researcher's questions. Second, information experiences and behaviours are usually investigated throughout a *process* of information seeking, following the user from uncertainty to understanding. While some individual posts collected in this study identified what stage of the childhood cancer experience the PCWC was experiencing and some posts were examined by the lens of various ISB models to identify specific behaviours (such as information poverty), none of the posts reflected PCWC throughout the entire childhood cancer experience and through a variety of information needs. Finally, as was addressed in the methodology (see Savolainen, 2011), members of online communities may present themselves and their information and support needs differently online than they would in person. This study was only able to investigate PCWC information needs and behaviours in an online environment, which not all PCWC participate in, and may not reflect daily PCWC information needs and behaviours.

5.3 Recommendations for future research

An ethnographic study, following families through the childhood cancer experience, could address the original research questions presented in the introduction and literature review and address the limitations of this study. Ethnographic studies have been used successfully in several ISB investigations. Primarily associated with the work of Elfreda Chatman, ethnographic studies allow the researcher to become immersed in the environment, build long-term relationships with the participants, and become an "insider" into a community (see Chatman, 1996). The key to ethnographic studies is establishing the researcher in the environment, allowing participants to feel comfortable sharing experiences with the researcher. One way to pursue an ethnographic study of PCWC information needs would be to establish a researcher based within the hospital, but with significant ties to outside organisations throughout the community – such as an information officer, or community support nurse. The researcher would be able to establish ties with families at diagnosis, and follow the family throughout various childhood cancer experiences, and throughout several cycles/experiences of the ISP. The researcher would be able to identify PCWC information/support needs as they arise, and study the process, challenges, and factors in successful information searches. A major limitation of this study was the inability to establish the demographics of the information user. As was shown by a review of ISB models (see section 2.1) information seeking behaviours and successful searches can largely be influenced by the user's previous experience of the subject, as well as their socio-economic background. The literature review and findings from the study also showed that family structures and roles could have an influence on information seeking and use of PCWC. By establishing close ties with families, a researcher would be able to identify and account for the effect of these precedent factors. An ethnographic study, following all aspects of the childhood cancer experience (both medical and support needs) would be able to judge the validity of the findings of this study; namely, are PCWC generally satisfied with the information provided to them by medical professionals, and how significant is the preference PCWC show for receiving information from other PCWC?

As was identified in the literature review (see Section 2.2) a large portion of research into the childhood cancer experience has focused on the development of PTSD (Norberg, A., Pöder, U., von Essen, L., 2011, Rodriguez et al, 2012, and Alderfer and Navsaria, 2009). The correlation between successful, purposeful information seeking and use and reduced risk of PTSD has already been shown (see Norberg, Linblad, and Boman, 2004). Likewise, it is known that a major contributing factor to PTSD is uncontrolled uncertainty in the childhood cancer experience. An ethnographic study of the information needs and behaviours of PCWC would provide further insight into how to help PCWC establish successful information seeking behaviours early in the childhood cancer experience, enabling PCWC to be proactive in the management of their child's treatment, and hopefully reducing the risk of developing PTSD. Studying the information needs would also indicate what the typical causes of uncertainty are for PCWC, and how to manage uncertainty.

In addition to ethnographic observation, PCWC should be questioned directly about their information needs and how they manage uncertainty. One method of accomplishing this is to ask PCWC to keep a diary of information and support needs as they arise. Diaries as a methodology in information seeking behaviour studies have been successfully used before (see Xie, 2009, and Kuhlthau, 1991). Used in tandem with other research methods (interviews and observations) diaries can be particularly helpful in tracking the information seeking process from the perspective of the user, and making the user more aware of the process. Employed correctly, diaries offer insight into users' needs and accompanying feelings, without relying on retrospective analysis. While it might be unrealistic to ask PCWC to keep a record of their information needs throughout the entire childhood cancer experience (which can last several years), the repeated use of diaries for a period of a week during critical periods in the cancer experience (such as a new diagnosis or new treatment) could prove useful in analysing the types of questions PCWC have and how/where they seek information.

One study that would be useful to replicate and account for advances in technology and medicine would be Rudolph et al (1981) study into how to develop an education program for PCWC. Although not conducted strictly from an information science perspective, Rudolph et al's study questioned the social, psychological, and educational needs and stresses of parents through a forty question postal survey to

PCWC. The survey also briefly examined PCWC preferences for receiving different types of information as well as how PCWC seek information in their own communities. The study was relatively small (with only 167 respondents), but showed how a survey specifically questioning the needs and behaviours of PCWC could lead directly to new services in PCWC support and education. An adaptation of Rudolph et al's study would need to include how PCWC use the internet to find information, as well as how PCWC interact with each other.

Finally, in addition to studying the information needs and behaviours of PCWC, future research should expand on the ISB of the entire family – particularly how information is shared between family members and with medical professionals. Some of the reviewed literature and collected posts touched on the role of PCWC as information gatekeepers for the child (see Anderzén-Carlsson et al, 2010 and Zwaanskwijk, et al, 20011). While the role of PCWC as information gatekeeper has been identified as part of the childhood cancer experience for PCWC, any research into how PCWC perform that role and the affect of being a gatekeeper on information experiences and familial relationships has been limited.

5.4 Recommendations for services

It appears from the literature review and the data collected from the study that PCWC identify *emotional/support* needs as a priority. The initiatives outlined in the introduction (particularly *Improving Outcomes: A strategy for cancer)* emphasize the coalition government's and support agencies' emphasis on improving patient experience and support, in tandem with improving medical care and survival rates (see section 1.5). Providing *emotional/support* information can be extremely difficult, as each family's situation is individual, and they will require different information at various points in the cancer experience. Furthermore, as was shown from the collection and categorization of posts, many PCWC are not able to identify and express information or support needs. In order to best support PCWC with their information needs (specifically *emotional/support* needs), support services should focus their services around the preferences and patterns identified in this study, and through the literature review. Namely, promoting PCWC networks, encouraging positive information experiences early in the childhood cancer experience, and fostering PCWC information seeking independence.

As PCWC have shown a preference for receiving information from other PCWC that have undergone similar experiences, the primary recommendation of this study is for support organisations to establish and promote networks for PCWC, and attempt to ensure that volunteers and staff of information and support services have personal experience with the childhood cancer experience. There appears to be a clear preference for PCWC to interact with other PCWC that have undergone the same type of cancer. Currently, CLIC Sargent provides information leaflets for individual types of childhood cancers, but only has one discussion forum on its website. Likewise, Macmillan has cancer-type specific forums, but they are combined for adult and child patients. The Macmillan and CLIC Sargent discussion forums could be significantly improved by having individual types of childhood cancer specific discussion threads available, which would aid PCWC in quickly identifying others that have undergone similar experiences, and allow them to feel more comfortable seeking information and sharing experiences. Where possible, medical and support professionals should encourage PCWC to network locally with other PCWC who are currently undergoing or have completed similar experiences.

A relationship for PCWC with information/support services should be established as early as possible within the childhood cancer experience. While the provision of information services will vary between health trusts, ideally information services and support should be available, and recommended, upon diagnosis to PCWC. If a hospital or medical unit is not able to provide a service themselves, they should encourage PCWC to proactively seek out information and support from established cancer organisations. Studies (including Jakobbsen and Holmberg, 2012, and Frostholm et al, 2005) have shown what information and how information should be presented during initial consultations, in order to minimize or manage uncertainty. Having a positive first experience (even if the information itself is negative) in the process of receiving information, and being encouraged to seek additional information, should help PCWC with the management of uncertainty throughout the childhood cancer experience.

Services should encourage PCWC to recognise their information needs, and educate PCWC on how to search for and use information for themselves. Medical professionals should also establish within the diagnosis consultation that PCWC are encouraged to ask questions and to prepare for future consultations by recording questions/concerns. Jakobbsen and Holmberg (2012) recently published findings indicating that patient satisfaction in receiving medical information was significantly increased by supplying patients with an information folder at diagnosis, with written information to support what was discussed in the consultation, as well as various forms of treatment and emotional support information. Patients in Jakobbsen and Holmberg's study were also encouraged to actively write down questions/concerns in preparation for future consultations, as well as to keep a diary of symptoms and treatments. The information folder was checked regularly by medical professionals, and patients were encouraged to carry it with them to all forms of appointments. While Jakobbsen and Holmberg concluded that "personal relations" between patients and staff members was the most salient aspect of patient satisfaction, "implementing enhanced information routines proved to meet patients' nursing information expectations" and improved communication between patients and medical professionals (Jakobbsen and Holmberg, 2012, pp. 187). In addition to providing basic written information to PCWC regarding their child's condition, medical professionals should attempt to educate PCWC on how to recognise, record, seek and use information for themselves in order to best manage the care of their child and manage uncertainty over the cancer experience.

5.4.1 Information Prescriptions

The use of 'information prescriptions' in childhood cancer could prove useful in encouraging PCWC to recognise their information and support needs, and to seek and use information. While information prescriptions have been used in a variety of ways in different health services, the Northumbria Healthcare NHS Foundation Trust has recently completed a successful trial of how to use information prescriptions (or information menus) for patients with long-term illnesses. Lesley McShane, the library information specialist in charge of the project, recently reported the findings of the pilot study at the 2012 Chartered Institute of Library and Information Professionals (CILIP) Health Library Group conference. The Northumbria NHS Foundation Trust encouraged consultants to complete an information prescription, covering a variety of information and support topics, for patients during a diagnosis consultation (see appendix for example prescription). Information professionals were positioned in a kiosk in the lobby of the hospital, where patients could approach them immediately after diagnosis and fulfil their information prescription. The information professionals would provide them with the leaflets and support information recommended by the consultant, but also encouraged patients to fill out their own information prescription sheet based on their perceived needs. Patients were recommended to other services by the information professionals (primarily charity organisations) and were encouraged to maintain contact with the information service throughout their treatment. McShane and her colleagues deemed the trial programme successful, as it:

- Streamlined information services to provide consistent, reliable information
- Encouraged patients to use support organisations and charities
- Made better use of clinician and nursing staff time
- Eased the burden of writing information leaflets by using information provided by charity organisations. (McShane, 2012)

The trial study conducted by Northumbria NHS trust appeared to be successful for a few reasons. One, the information prescription was completed at the time of diagnosis (with consultants reporting that completing the prescription did not negatively impact consultation time). Fulfilling the information prescription, and interacting with an information professional was then available immediately following the consultation. Information provided to patients was screened for consistency and reliability, but also came from a variety of sources, in order to encourage patients to seek information and support from sources other than their medical professionals. In order for an information prescription service to be successfully run for PCWC undergoing the childhood cancer experience, protocol similar to Northumbria NHS Trust's should be taken. Information services should be made available upon diagnosis. Information should be screened for validity and consistency (and meet Information Standards), but should be from a variety of sources. The protocol of having patients complete their own information prescription would not only allow information professionals to better serve patients' immediate needs, but could provide data for a study into PCWC information needs upon diagnosis, and allow researchers to examine differences between medical professionals' assessment of information needs and how PCWC perceive their own needs.

5.5 Conclusions

While this study was not an exhaustive examination of PCWC information needs and behaviours, the study did provide insight regarding preferences that PCWC exhibit. During the iterative pattern coding process, the information need of *similar experiences* was established. Ultimately, PCWC seeking *similar experiences* had the highest rate of incidence among the collected posts, indicating that PCWC express a preference for receiving information from other PCWC who have undergone similar experiences. In comparison to the literature review, the incidence rates of PCWC searching for *disease*, *treatment*, and *practical/daily life information* were all surprisingly low. The collected posts also indicated that significant events in the childhood cancer experience (diagnosis, new symptoms, palliative care) could initiate new information needs and caused uncertainty.

Based on the findings from the study, the primary recommendation for services was to encourage PCWC to network with each other, by establishing local support communities, and improving cancer support websites to allow PCWC to post topics in childhood cancer-specific forums. It was also recommended that medical and support services could improve their information provision, and help to reduce uncertainty, by establishing the role of information provision at diagnosis and providing positive information experiences early in the childhood cancer experience. The recommendations to services support current initiatives (such as the ICCPO *Guidelines for standards of treatment and care* and the Coalition Government's *Improving outcomes: a strategy for cancer*) by improving information support to empower cancer patients and their families, increase chances of survival, and make medical and support services more consistent within the United Kingdom.

Recommendations for further study focused on an ethnographic study that would follow families throughout the childhood cancer experience. Following families through the cancer experience would allow researchers to better view the variety of information needs and preferred sources of PCWC, as well as account for how demographics and antecedents to searches influence PCWC ISB. Most importantly, an ethnographic study would allow researchers to follow PCWC through complete cycles of information seeking, and gain understanding of how PCWC manage uncertainty.

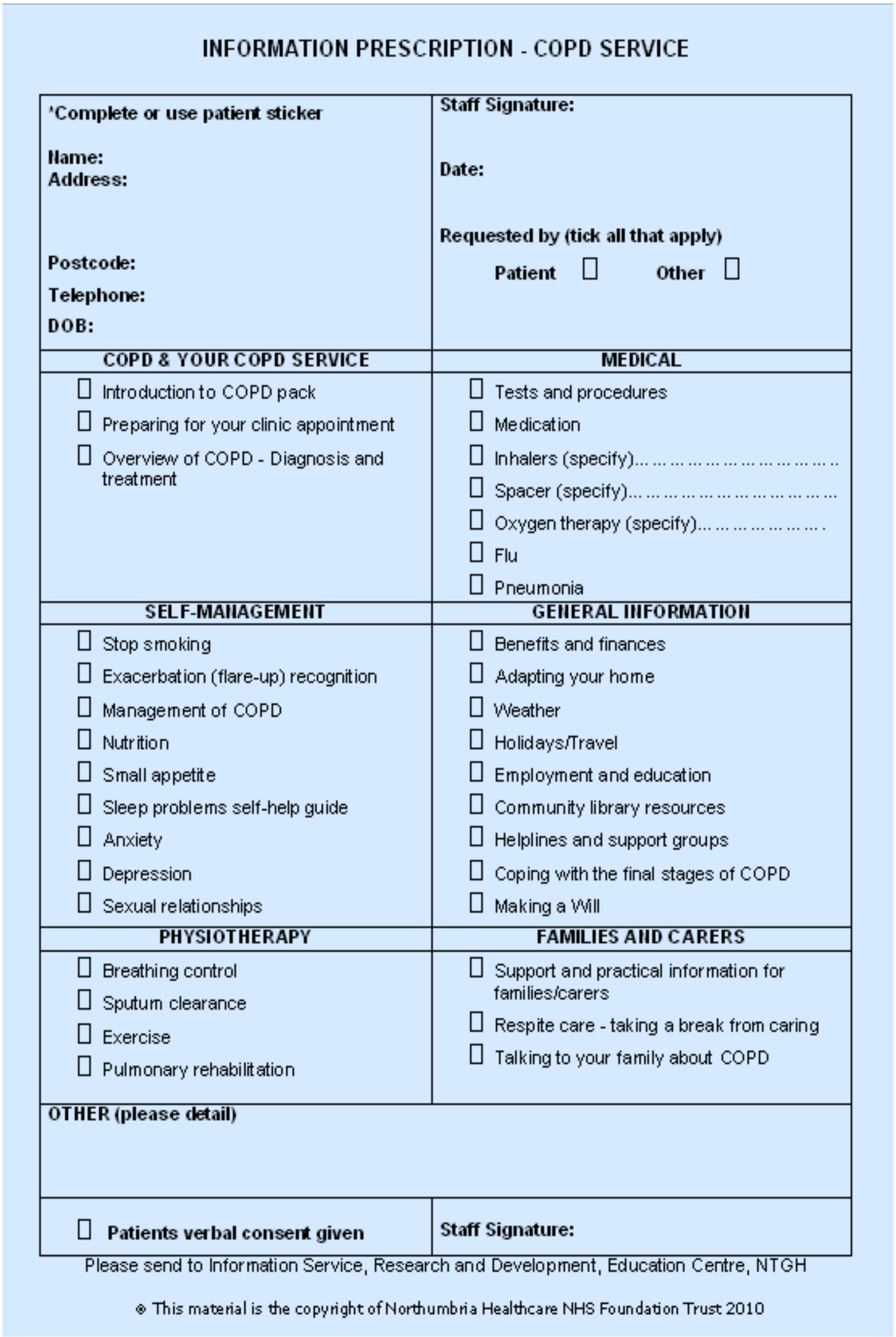
This MSc study employed an emergent methodology of reviewing archived posts from online discussion forums. While not the original choice of methodology, the methodology was chosen because of the time constraints of the study and the opportunity it provided of gathering first-hand, candid accounts from PCWC. A major limitation of the methodology was that PCWC did not respond directly to research questions, and all of the data gathered and coded was possibly influenced by the researcher's bias. However, consistent patterns of information needs and preferences emerged from the coded data, indicating that the methodology did provide useful, reliable insight into the information needs of PCWC as presented on online discussion forums. Accounting for differences of how individuals interact and behave online versus in person, reviewing archived posts can prove to be a useful methodology for gathering data regarding the information needs of specific communities.

5.6 Researcher's reflections

Originally, this project was designed to receive feedback from local PCWC via semi-structured interviews on how to improve information services. However, the change in methodology and research questions proved to be very useful, as the researcher was allowed the opportunity to experiment with how to employ an emergent methodology, including how to define initial categories based on a literature search, and how to use iterative pattern coding to establish patterns of information seeking. In addition to gaining a better understanding of how to undertake quantitative research, the application of analysing posts according to various models of ISB provided an opportunity to conduct qualitative research, and provided the researcher with a deeper understanding of fundamental models of ISB. While this research project provided initial, basic indications of PCWC information needs and preferences, the researcher was often frustrated that she couldn't gain additional information regarding the search queries (including antecedents), or follow PCWC through information seeking cycles to determine actions that led PCWC from uncertainty to understanding. If the researcher were to continue to study ISB of

PCWC more in depth, she would undertake an ethnographic observation, as described in the conclusions and recommendations.

APPENDIX – INFORMATION PRESCRIPTION



INFORMATION PRESCRIPTION - COPD SERVICE

***Complete or use patient sticker** **Name:** **Address:** **Postcode:** **Telephone:** **DOB:**	**Staff Signature:** **Date:** **Requested by (tick all that apply)** **Patient** ☐ **Other** ☐
COPD & YOUR COPD SERVICE	**MEDICAL**
☐ Introduction to COPD pack ☐ Preparing for your clinic appointment ☐ Overview of COPD - Diagnosis and treatment	☐ Tests and procedures ☐ Medication ☐ Inhalers (specify)…………………………….. ☐ Spacer (specify)…………………………… ☐ Oxygen therapy (specify)……………………. . ☐ Flu ☐ Pneumonia
SELF-MANAGEMENT	**GENERAL INFORMATION**
☐ Stop smoking ☐ Exacerbation (flare-up) recognition ☐ Management of COPD ☐ Nutrition ☐ Small appetite ☐ Sleep problems self-help guide ☐ Anxiety ☐ Depression ☐ Sexual relationships	☐ Benefits and finances ☐ Adapting your home ☐ Weather ☐ Holidays/Travel ☐ Employment and education ☐ Community library resources ☐ Helplines and support groups ☐ Coping with the final stages of COPD ☐ Making a Will
PHYSIOTHERAPY	**FAMILIES AND CARERS**
☐ Breathing control ☐ Sputum clearance ☐ Exercise ☐ Pulmonary rehabilitation	☐ Support and practical information for families/carers ☐ Respite care - taking a break from caring ☐ Talking to your family about COPD
OTHER (please detail)	
☐ **Patients verbal consent given**	**Staff Signature:**

Please send to Information Service, Research and Development, Education Centre, NTGH

McShane, 2012.

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