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Designing for the Experience of Pain

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1. Introduction

Pain management within a palliative care context offers many opportunities for designers to innovatively push boundaries as they provide new perspectives on experiences. Additionally, the designer's ability to remain grounded in the needs of the care environment is dependent on their ability to draw on the experiences of others. This paper discusses the importance of experience and the way it can be explored as a key problem-solving tool. Experiential research aims to guide the design process and subsequent solutions towards products and systems that are deeply rooted in the needs of pain sufferers.

Breakthroughs in science and technology have led to the development and implementation of innovative concepts, which have shaped and improved the lives of pain sufferers. Innovations such as Transdermal Patches, TeleMedCare Health Monitor and NeuroTherm radiofrequency nerve ablation systems have been nurtured, guided and bought to realisation as physical products by diverse and skilled professionals in the field of science, medicine, engineering and design.

As the realm of pain management in palliative care becomes both broader in its capabilities and highly specific in application, designers are asking the question, "How do we design for a pain sufferer if we have not experienced that for which we are designing?" There are various tools and strategies available to designers to ensure innovative solutions are formulated, but the initial problem must still be defined. Similarly, the solution must reflect the values and cultural beliefs of the community.

In order for products and systems to maintain innovation, the design process may involve experiential research. There are difficulties associated with this, primarily due to cost and timing but also communication barriers, cultural differences and availability of resources. If this key research activity is not undertaken, there is potential for pain management products to be disengaged from daily experience. The importance and placement of experiential research within the design process and the greater development of pain management products will be discussed in this paper.

2. Concepts

2.1 The role of experience in shaping our understanding

Our perception of the environment we encounter will be affected consciously to some degree by everything we have learned about it up until now (Hughes, 2000). These

perceptions are driven by a culmination of experience, knowledge, memory, reflection and analysis. It is through experience that we are able to analyse the present and imagine for the future.

Experience may define to a large extent of who we are, what we do and what we have done (Bate and Robert, 2007); however it is not necessarily understood very well. Subsequently, it may be questionable as to why the study of experience is important in our understanding and development of services, systems, and processes and in the subject of this paper, design. As researchers and developers of community resources, designers could develop for behaviour which is observable or attitudes which are measurable (Bate and Robert, 2007), however our behaviours, attitudes, logic, memories, opinions, actions and reactions are interpreted through personal and social significance gained through experience (Suri, 2002). By addressing the core experience or couplings of experience, designers are able to build relationships of phenomena and strongly address the needs of the user.

Bate and Robert (2007) describe the elements of experience on page 41 as

- Reflection and awareness (awareness of self, others and the environment in a conscious and subconscious manner)
- Sensation (kinaesthetic)
- Perceptions
- Thought
- Memory
- Imagination
- Emotions and expressions
- Desire
- Actions and conduct

Within each experience, the levels and impact of these elements may be minimal or maximal. During an experience, it may be unlikely that individuals are identifying, recording and reflecting upon such elements. The challenge for researchers is guiding individuals in their reflection of such elements in a meaningful manner, which will allow insightful contribution to the design process.

The design profession requires experience, as it will lead to a change in perspective from which the problem is defined. Hubbell (1994, p61) describes this process: "Experiential analysis is a form of research that encourages the researcher to use a variety of alternate techniques as a means of learning about a particular socio-political phenomenon." Through the experience, the designer comes face to face with the problem. Examination of the elements allows for problems to be identified, prejudices to be overcome, the ability to reflect on that which is not normally acknowledged and the time to formulate solutions that directly relate to the context. This allows the initial design process to be led by the context and those within it as opposed to user testing a prototype several stages down the track.

Experience design can be applicable to any field in which creative process and cross-pollination of ideas results in a designable scenario. Chapman (2005) explores the potential for experience and states, "The most important concept to grasp is that all experiences are important and that we can learn from them, whether they are traditional, physical, offline experiences or whether they are digital, online or technological experiences."

Experiential research offers the greatest opportunity for all areas of the context to be explored, for all disciplines to offer perspectives and for the focus of product development to be driven by the key user groups. This form of investigation is crucial within the early stages of design development, prior to attachment of ideas, materials and technologies.

Although several areas of discourse would benefit from the inclusion of experiential research during investigative design phase, the following discussion is formulated around the palliative care environment.

2.2 The palliative environment as a design setting

Australians are becoming increasingly aware of the cost and financial expenditure of healthcare, especially as the aging workforce moves towards retirement. The Australian Government budget estimates that there are approximately two million Australians aged over 70 years, with this figure expected to double by 2029. The Minister for Health and Aging acknowledged that each year more than 20,000 Australians receive some form of specialist palliative care and more than 500,000 patients, carers and families are affected (Elliot and Roxon, 2010).

In 2010, the Australian government dedicated a further \$14.3 million to fund projects for improved palliative care services, research, training and information (Elliot and Roxon, 2010). Acknowledgment of the current need for investment in palliative care to create a health care system that has service sustainability provides incentive for the growing numbers of professionals looking at ways of contributing to this field.

As a service industry, the health care sector draws on the products and resources that have been developed and produced by the private sector. The private sector is therefore most likely see the greatest development and generation of consumer products, systems and services that will cater for the growing palliative market. It is important that the priorities of communities and individuals will be recognised in the commercialisation process of the private sector with the additional investment of time and funds by governments globally. It is on this level that experiential research and data that is collected will become most valuable to the developing body, with innovations reflecting the insights gained through this alternative, experience-centred perspective.

Products, systems and environments are rarely experienced without some kind of service affiliation (Suri, 2002). Suri (2002, p162) illustrates this trait through the example of the overall quality of interaction with a telephone or a hotel having as much to do with the characteristics of the service encountered as with the design of the physical elements interacted with. Service industries are commonly associated with corporations that are customer service focused such as hospitality franchises, information technology and telecommunications companies, whereby the customer experience is a crucial element of the company's evaluation of performance.

For example, telecommunications companies are able to provide the customer with the physical artefact of a mobile phone, which has been designed to be ergonomic, aesthetically pleasing, and inclusive of emerging telecommunications technology. Once connected to a service provider, the capabilities of the phone extend well beyond the physical elements to a

realm of digital interaction. Throughout the use, the customer will evaluate both the physical artefact itself and the corresponding service. At times, the individual may not be able to differentiate between the two and might mistake poor performance as either physically or service related. Subsequently, this affects the experience that the customer has of both the phone and the service.

Within healthcare environments, patients are not referred to as customers. Healthcare does, however, provide services, expectations and discussions like any service industry. Receiving institutionalised care for a period of time, patients are more likely to evaluate the more complex elements of experience. Berry (2006) comments on this idea by stating 'few service experiences are more important, variable, complex and personal than being hospitalised and patients are likely to be eager for any evidence of the hospital's competence and caring'. Although this statement comments on the environment of a hospital, this idea may be applied to any notion of care that is provided to patients and generates care experiences.

Australian attitudes and behaviours in responding to death and the environment in which this occurs are derived for the most part from our English heritage (Kellehear, 2002). As the dying population within Australia (i.e the proportion of the population within their final years) becomes multicultural, perspectives on the ideal palliative care services and the way in which they meet personal identity and social needs will challenge these environments, those who provide care and the subsequent device and systems designed to be used in administering care.

It is also acknowledged that the needs of palliative care patients are becoming more complex as many patients may not suffer of one life threatening disease but a culmination of several physical and psychological ailments (Dale et al, 2009). This in turn changes the predictability of a patient's journey and experience as they enter the palliative phase.

Although it has been identified as a service industry, there are also unique qualities that separate palliative care from general healthcare. The role of this form of care-giving is to provide a support framework for the patient and provide a central, long-term care system for health professionals and family members as trust and friendship are built over the period (Ersek and Wilson, 2003). It is a multidisciplinary, holistic approach to care that encompasses physical, emotional and spiritual needs (Noell, 1995). The palliative approach is particularly unique as the care focus becomes concerned with alleviating symptoms such as pain as opposed to treating the illness directly.

Furthermore, in extending the care environment to the physical environment, it is important to acknowledge that devices, objects and systems impact all levels of care. Noell (1995), states that communities should be seeking to "highlight the quality of the human experience and shift medical services and dehumanising equipment into the background", and that "a physical environment for older people must be designed to celebrate life". Medical devices, services and equipment are important, and in some cases crucial, to the care of patients. Noell (1995) has also brought to the attention of developers the need to be exploring the innovation of emotionally rich interactions (Djadjadiningrat et al, 2002). Through a greater understanding of both the emotional and physical requirements, designers are provided with the opportunity to alter the experience of palliative care and interaction through innovation.

Such interactions may become the driving force for problem identification as the designer moves towards creating for the experience as opposed to the development of a product. Bate and Robert, (2007) use the example of seeing not a glass half empty or a glass half full, but questioning as to why it is a glass at all. Through this questioning phase, designers are able to generate ideas for the experience of drinking water as opposed to producing a glass, thus opening a greater spectrum of possibility. In the realm of medical design, the complexity of the product most often extends beyond the simplicity of a glass. Nanotechnology, remote telecommunication and interactive materials are only skimming the surface in the depth of technologies employed within healthcare.

Due to technological development, there is a greater emphasis on a carer's ability to be technologically competent and proficient. New technologies allow carers to perform their role efficiently, effectively and accurately, however there is concern that the care provided is governed by the physicality of an object (Locsin, 2005). This notion is also applicable for palliative patients, as their quality of life is greatly affected, and can be restricted, by the functionality of medical devices.

Beyond technical aspects, our perception of products and our response to them is not solely an outcome of cognitive processing but also an emotional response. There is a particular manner in which humans feel and perceive the tactile and aesthetic nature of a product (Suri, 2002). Consumers will often consider the way in which a product reflects their current lifestyle whilst also aspiring to a projected lifestyle. Issues of aesthetics, functionality and past experience will guide the consumer in making informed choices that determine future experiences.

Suri (2002, p163) further develops this through the example of purchasing a briefcase, Individuals may consider the aesthetic and practical issues involved with using a briefcase such as capacity and features that may be needed as well the message that the bag portrays within the community. Terms such as 'serious', 'professional', 'arty' or 'hip' may be used as a way of individuals classifying the emotional and physical characteristics of the briefcase based on their understanding of the objects meaning. Through this example it becomes clear that prior to making a purchase, it is possible for individuals to build a relationship with an object based on both past and projected future experiences.

Additionally, emotional responses play a role in consumers' expectations and affordances offered to a product. Djadjadiningrat et al (2002) discuss' the role of applying respect within the foundations of a products sensibility. Through the comparison of a vending machine with a sales assistant, Djadjadiningrat et al (2002), encourage not only designers and the product development team but also most importantly consumers to question acceptable and desirable interactions of use within innate products.

When considering the same perspective in a pain management device, the provision given to individual experience, cultural context, communication barriers, emotional requirements and changing physical condition is very different. The considerations of size, shape and materiality are still equally important however the choices are limited to functionality.

The following section of this paper explores the role of the subcutaneous syringe driver in managing pain for palliative patients. This product was chosen as a case study as the

experiences and functionality of the product are complex and multiple, therefore allowing for a detailed analysis. This case study will demonstrate the importance of acknowledging experience in development of new syringe driver models in the future.

2.3 Pain management: palliative care principle

The goals of palliative care as outlined by The Therapeutic Guidelines – Palliative Care – of Australia (2005) are;

- To provide relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological, emotional, spiritual and social aspects of care for the patient, the family and close carers in a culturally sensitive manner
- Offers a support system to help patients live their lives as actively as possible
- Offers a support system to help the family and carers cope during the patient's illness and the patient's death.

The Therapeutic Guidelines – Palliative Care – of Australia (2005) acknowledges that there are potential problems in providing palliative care within Australian communities. The inability to provide high quality care is often due to relatively low staffing levels (both nurses and other members of the palliative team) and the possibility of having limited access to outside expertise due to funding restrictions and the consequent lack of resources.

The first goal of palliative care, to provide relief from pain and other distressing symptoms, involves multiple and varied experiences which in turn affect the subsequent mentioned goals. Through a greater understanding of the pain experience, it is felt that improved systems, products and environments may result which in turn will improve the overall palliative experience.

The International Association defines pain for the Study of Pain as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.' (The Therapeutic Guidelines – Palliative Care – of Australia, 2005)

Pain has the ability to affect a patient's physical response and condition in conjunction with affecting their psychological mood. It is acknowledged that pain is a personal experience whereby the experience and perception of pain is influenced by a patient's state of mind. If pain is a subjective experience, then the care environment should in turn recognise and treat the pain as described and reflected by the patient (Wilson, 2007).

As discussed earlier, the palliative patient is more often suffering from numerous diseases which will affect their ability to describe, analyse and reflect on their acceptance and experience of pain. Furthermore, two patients may be suffering from similar sensation of pain, but their experience of the pain may be different.

This creates barriers to effective pain management and makes the task of gathering experiential data all the more difficult. In Section 2 this paper, possible strategies will be explored that may be employed in order to gain a greater understanding of the experience

of pain for not only designers but also for the health care industry and for the greater product development team.

3. Frameworks

3.1 The use of narratives in analysing experience

As an individual moves into the palliative phase, the power to communicate emotions, thoughts, and medical needs is extended beyond the patient to those that surround and care for them. The following description has been given by a chaplain after holding a discussion with a patient "...terminally ill or extremely distressed, in pain suffering extreme handicap, or suffering from something that makes life hard for them to bear, they feel that they are completely useless. They feel that they have nothing to give and that the person with them is giving everything and they are receiving; whereas in fact, they are giving out an enormous amount without even knowing it. In fact I found that very ill people generate a tremendous spiritual energy and for the most part they are quite unaware of it. When you tell them that they are giving you back something of immense importance, they can't understand what you are saying. But it is tremendously real." (Jenkins, 1997)

As humans, we tell stories often and in a variety of manners whether verbal or written, through motion and sound, collections of images and the use of props. Story telling offers the opportunity for individuals to culminate their interpretations, emotions and responses in a way that is personal. Through an audience or a story told to ones' self, the narrative is a natural way of recounting an experience in a structured form (Moen (2006). Through the narrative, a sequence of events is recalled and individual thoughts are captured. Stories may include elements that are not always easily identifiable or directly relevant and offer much greater value than that of a structured interview.

The narrative research approach has been growing in use as researchers have become aware of the possibilities and opportunities that it can offer as a way of learning about context, interaction, culture and perception. Although storytellers may alter, opine, exaggerate and hypothesise, the story itself offers a vivid reflection on the experience being described (Bate & Robert (2007). Through rich descriptions, the mind of the listener is able to wander, reflect, interpret and imagine the event, with the hope of building a foundation of the experiential narratives.

The palliative environment is rooted in the relationships that are built over time. These relationships are founded on trust and friendship that will have built through discussions and stories as patients and carers describe the experiences of entering end of life care. Over the past 25 years there has been an increase in published stories of both carers and patients facing the prospect and the stage of being within palliative care (Bingley et al, 2008). As identified earlier, the palliative experience is difficult to explore and analyse first hand, resulting in research that may be quantitative and statistics based. Stories offer an insight into the complex experiences of end of life care as recounted by the environment and act as a key research tool to designers in the development of pain management tools.

The validity of stories and narratives can be questioned and analysed. Bingley et al (2008) identify key narrative analysis methods that can be implemented for the review of research.

These methods explore the analysis of stories in terms of life grid timelines, through the structure and the form, through a holistic approach of stories or a sequence of stories and through biographical analysis whereby the same biography is presented by a variety of individuals. These techniques allow for narratives to be interpreted and translated by researchers and allow for the greatest amount of value to be sought.

Researchers may explore the narratives in such analytical ways as listed above, however designers often iterate between design research, practise and process whereby the analysis of the narrative is incorporated within design responses. The experiences of patients and carers as collected through narratives offer designers the opportunity to co-design with the environment. As the sequence of narratives expands, designers are able to pose solutions and responses to the environment with the hope of further narratives developing.

The palliative environment offers both unique and challenging obstacles in the drawing of narratives as a reference material. Traditionally user studies in the design field are based on an object centric perspective (Redstrom, 2005) whereby designers are able to explore a context through existing products and rituals of use. Although this process will lead to innovative progression in product development, the integration and use of narratives aims to redirect development towards rituals of experience, thus encapsulates a much larger spectrum of ideas.

Palliative Care Australia, in collaboration with patients and carers, produced a collection of stories in 2007 written by those that have followed the palliative journey. This initiative not only performs as a research base but also allowed individuals the opportunity to share, educate and heal through the act of writing.

Gai Gibson shared the story of her husband Greg who was diagnosed with lung cancer. Gai recounted the successes and trails of the palliative environment as she and her family experienced it. Phrases such as “We tried going to day procedures on the first occasion but they didn’t even have a bed to lie on, just a very hard recliner chair”, conjure images in the mind of a sparse room, the hard square recliner chair, the difficulties of mobility for the ill, the anxiety for Greg as he would need to lie for a long period of time and the overwhelming feelings that Greg and Gai must have felt when entering into a foreign medical environment. Although the story has been interpreted and assumptions have been made in relation to the physical and emotional aspects of this narrative, this interpretation has been made by the researchers linking similar personal experience. Researchers may make further analyses of the stories and develop critical links, for example is the hard recliner chair similar to that of a dentist chair. This will lead to identification of where design subjects overlap.

Further into the story, Gai states “For what was once a simple trip into town we now needed to take a seemingly endless list of supplies, including oxygen cylinders; an oxygen conserving device; wheelchair; Roho cushion; mask as well as nasal prongs; morphine nasal spray; Ventolin and mobile phone in case of breakdown, A doctor’s appointment at 11:00am required as to make a start at 7:30am – the care was constant.” This statement allows for empathy to be generated between the reader and Gai. Gai’s reflection may spark previous

experience for parents that have had sick children, or those that have had to take an elderly relative out for a day. It is these connections that we draw between the experiences of others and those that are personal that act a foundation for problem analysis.

The design profession is posed with the task of making this trip easier, by simplifying objects, by making the oxygen cylinder lighter or more compact, by simply reducing the number of tasks needed to get from the home to the doctor. Designers may turn to inspiration from children's prams, luggage design and compact storage systems to draw design qualities and innovations that may add value to this environment. Innovations in commercial markets can be utilised and adapted for use in the medical field.

These narratives build a collection of experiences in which the designer can begin to map the areas of concern. It provides the designer with the ability to follow a progression of experience by first entering into the context, learning about the context as it exists, hypothesise about the ideal experience and responding with a concept. Although technologies, resources, manufacturing and materials manipulate the product development process, budgets and timelines, this particular progression allows the practises of medicine and design to inspire and co-create.

3.2 Experience based co-design

Co-design or co-creation of products, is a term that is often associated with marketing infrastructure whereby the customer is given the opportunity to yield some form ownership over the design process. This tool is often seen as a way of improving customer satisfaction within products whilst also allowing variance and personalisation of products in a large market. In corporations such as motoring, telecommunications and fast moving consumer goods, the majority of participation is generated through the use of multimedia and multi channel process whereby customers can contribute remotely to the questions or ideas posed by developers and manufacturers (Pini, 2009). When comparing this to the medical service industry, the process of generation and collaboration should occur differently based on the introduction of experience.

As analysed earlier, the generation of narratives allows for the co-design and generation of ideas to occur at the root level of experience. This is particularly important, as the range of range of products that may be utilised in the treatment of pain is much narrower than that of other fields. The design process for medical devices may also be considerably longer and complex, resulting in fewer developments and options available to patients at any one point in time.

Through the collaboration of the palliative environment with designers, engineers, scientists and manufacturers, it is hoped that the resulting products will be able to provide for the market more effectively and efficiently. It is also hoped that as the collaborations take place, a database of experiences, inspirations and ideas will culminate and therefore the process will develop more rapidly.

The translation and communication of ideas within the collaborative framework may occur through the generation of storyboards, mind-maps, analogies, props, photographs, short films, personas, touch points, brainstorming and sketching (Makela, 2006).

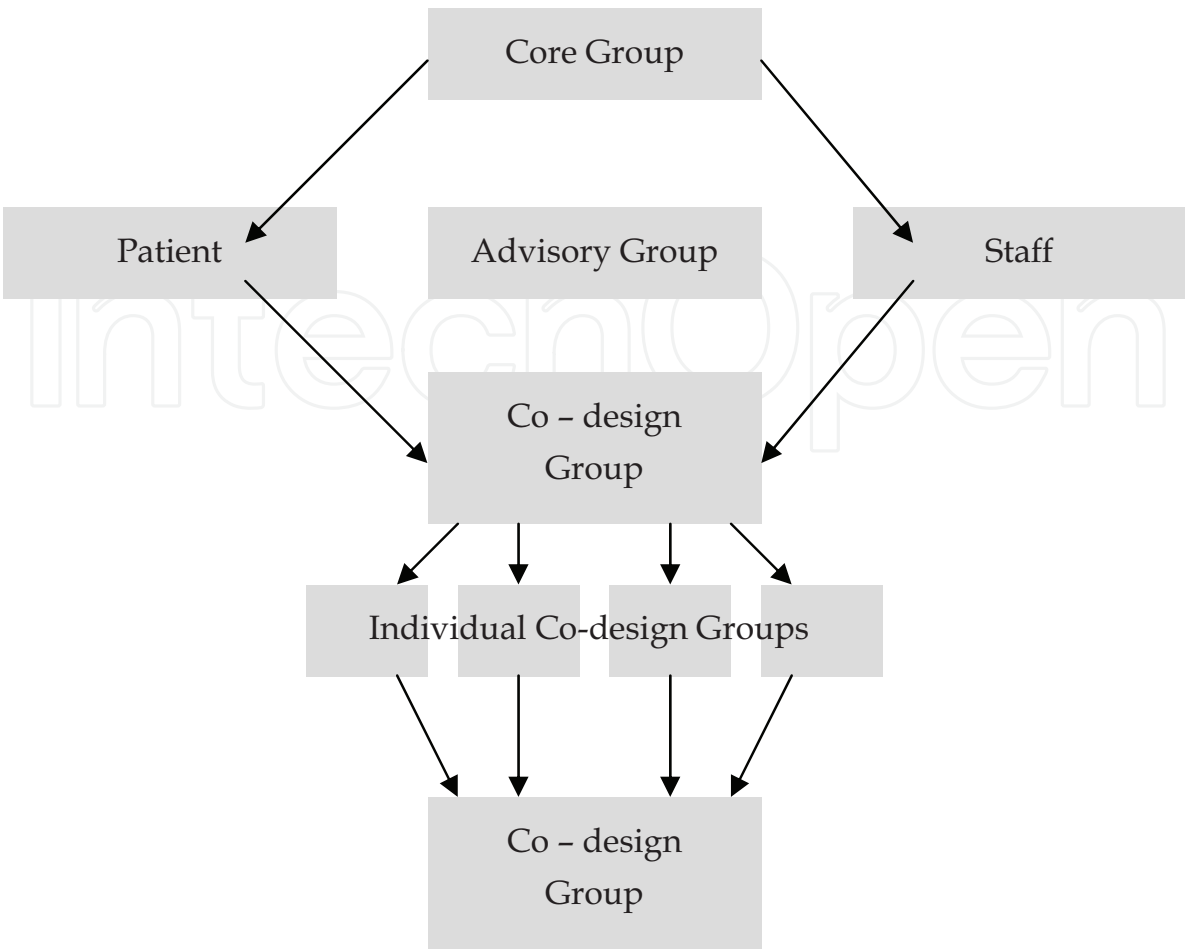


Fig. 1. The experience based co- design process abstract from *Bringing User Experience to Healthcare Improvement* by Bate and Robert (2006) on page 120.

Bate and Robert (2007) identified key groups in the experience based design process. Through this process the leadership is shared between patients and staff as they distinguish the common needs and requirements for the co development process. The identification of a core group turns attention towards the needs of all those that come into contact with the environment as opposed to a purely patient led or user led process.

Figure 1 has been drawn from Bate and Robert’s study *Bringing User Experience to Healthcare Improvement* (2007 p120). This process map offers a visual indication as to the various groups that encompass the co-design process. It is important to acknowledge the specialised skills of the development team such as designers and engineers. Although the aim of co-design is to allow collaboration and a continuous feedback cycle, there is knowledge and skills that designers possess and also draw upon from external sources in order to best lead the design process.

Figure 2 illustrates the way in which the co-design and design process may flow in an experience design situation. The design process may be fluid, stagnant, structured or disjointed in its progression, dependent on designer’s style and discipline. Throughout, the designer must retain direction to ensure that paths of exploration can be executed within a design solution.

The design process may involve a cycle of progressions, and the core group, patients and carers may be drawn upon at several stages along the process. Although the figure demonstrates a somewhat structured direction, the designer may move backward and forward amongst the collaborators as ideas are explored, questioned and reviewed.

The designer's priority during the co-design process is to act as an agent for those within the palliative framework. The final design solution(s) will represent the partnership between patients, carers and specialists, in a resolved product that can be presented and communicated to manufacturers, government bodies, specialist developers and investors within the private sector. By drawing on experiences, interactions, feedback and inspiration, the product solution will quantify the needs of palliative care.

The subcutaneous syringe driver is a pain management tool that is utilised within palliative care. This particular product has been the focus of review within Australia since the primary model was withdrawn from the Australian market in 2007. The operation and interaction of syringe drivers requires numerous processes and effects several members of the palliative care team. The experiential design model will be applied to the syringe driver in the form of a case study to explore the relationship between experience, product design and the palliative framework.

4. Practise and process

4.1 Case study - syringe driver

A syringe driver is a power driven device for pushing the plunger of a syringe forward at an accurately controlled rate. Syringe drivers are used within palliative care environments as a primary way of conducting pain management for patients who suffer from chronic pain through the implementation of pharmacology.

The medication is administered through the subcutaneous route and diminishes the need for constant injections whilst allowing adequate pain medication levels. Nurses are able to mix together 3- 4 drugs in a syringe and set the device for 24 hours. This elevates stress and anxiety for the patient, as they are able to perform daily rituals such as eating and sleeping without the worry of having to engage with a device for pain management.

There are several models of syringe drivers available on the Australian market and many of these are utilised daily within hospitals, nursing homes, hospices and homes around the country. The primary model, the Graseby MS26, has been withdrawn from the Australian market for purchase but will remain operable within Australia until November 2012. As a result, the Australian government has sourced replacement models that meet the Australian Therapeutic Guidelines and all practise standards and has communicated these suggested models to palliative networks around the country. Although an opportunity for critique and revitalisation of such devices has arisen, barriers such as timing, financial, resource availability, private sector investment and added medical value, has resulted in the provision of replacement as opposed to regeneration. Image 1 presents the functions and key features of the primary model, the Graseby MS26.

The following discussion explores the implementation of experience-based models in the reflection and redefinition of medical processes and service.

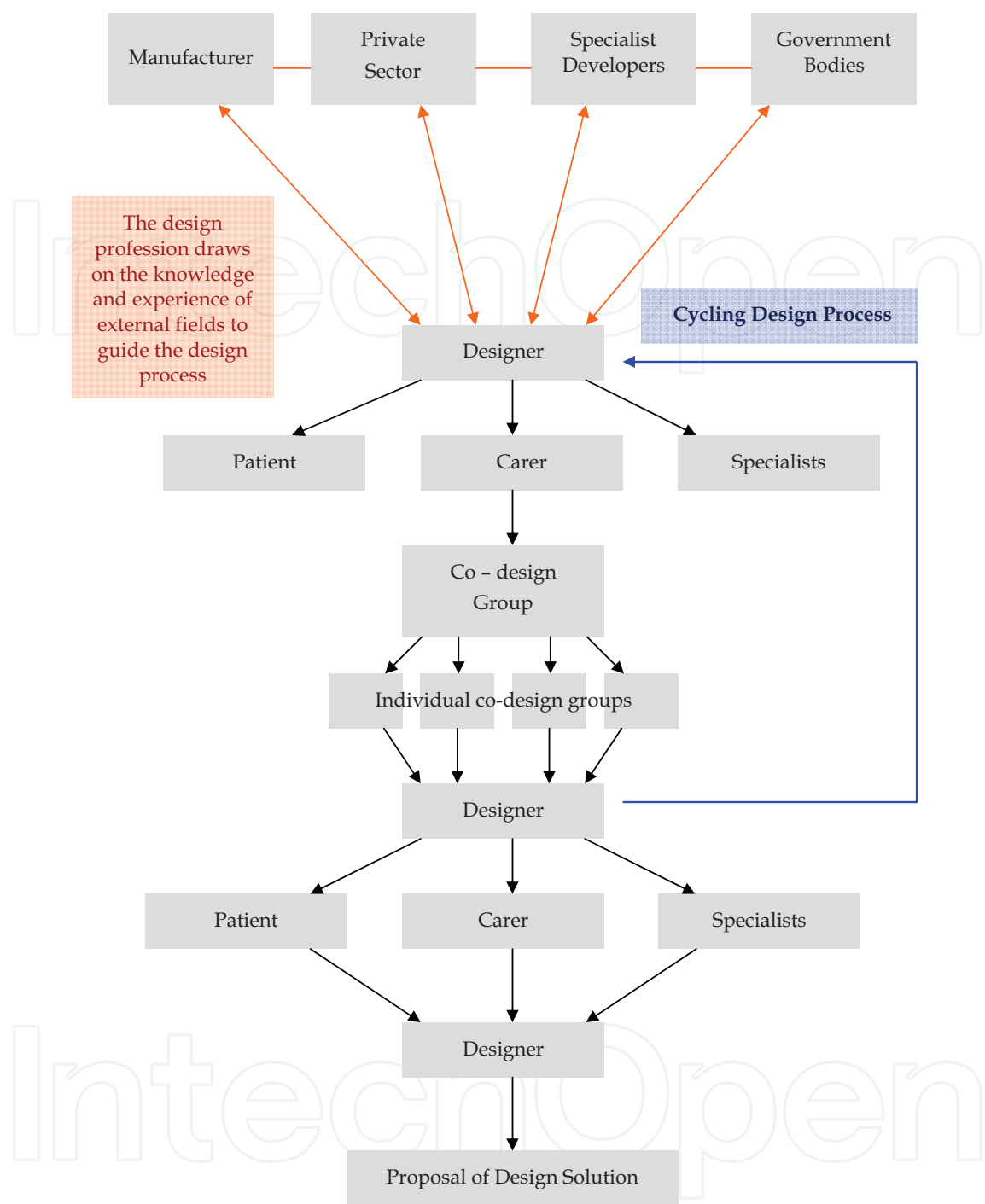


Fig. 2. The experiential design process model.

4.2 From object to user to experience

Over time designers have been exploring the relationship between objects and humans, either through aesthetics, function, materiality, experience, rituals, technology and the natural environment. Different design movements have explored fundamental design principles and have contributed to the design approach both practised and taught amongst the design community.

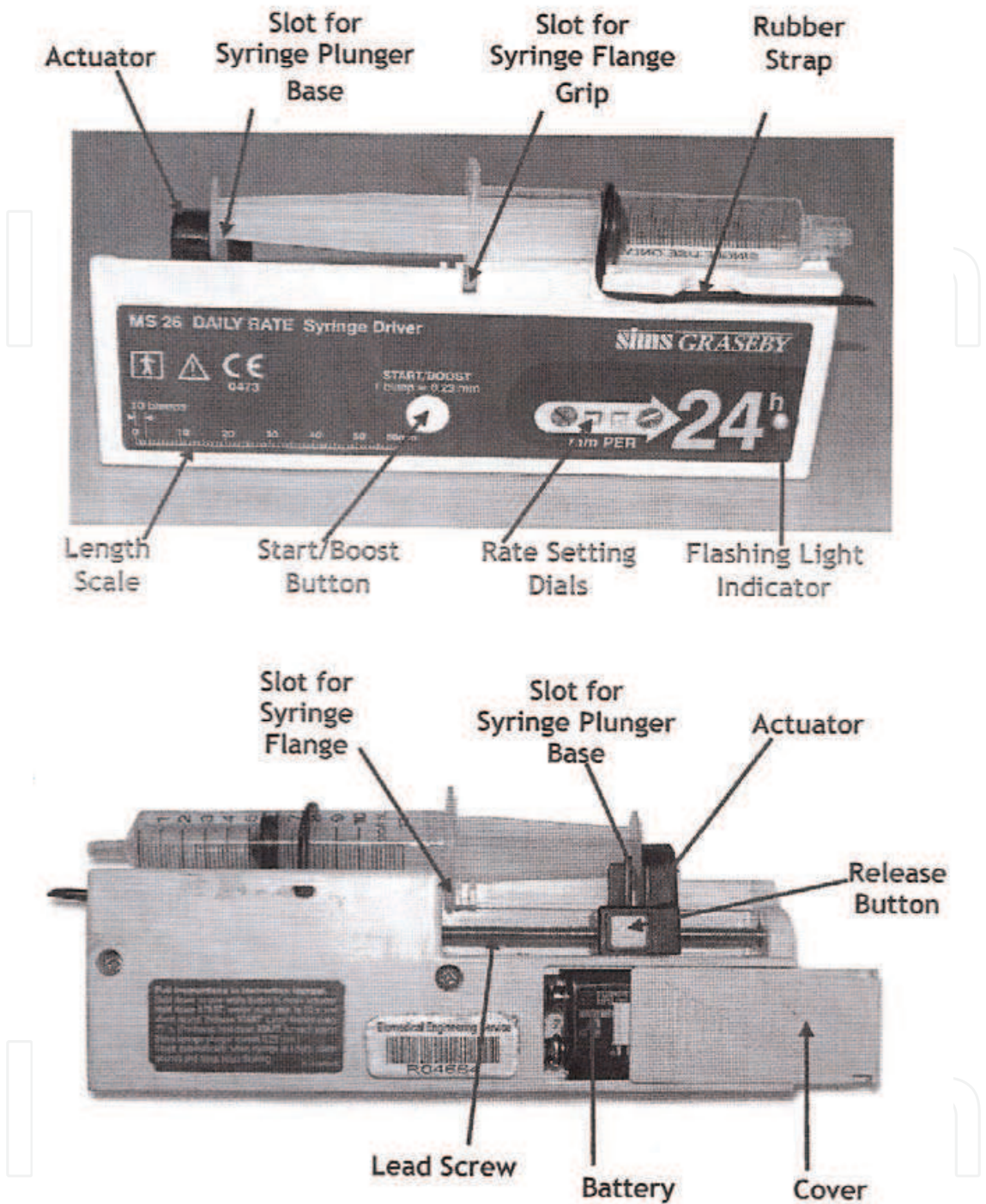


Image 1. Key Functions and Features of the Graseby MS26 (Ballarat Health Services, 2004).

The exploration of syringe driver practise and review would commonly begin with an analysis of current rituals, processes, engagement, satisfactions and disappointments centred on the object and its intended user. The explorative phase occurs on the premise that there is an active product in which to review, that the relationship built between object and user is centred on the capabilities of the object and the way in which the object fits to the user needs and desires. This form of exploration is demonstrated in Figure 3. By placing the syringe at the centre of interaction, users such as patients, carers and specialists must engage with the syringe driver to carry out daily rituals and behaviours.

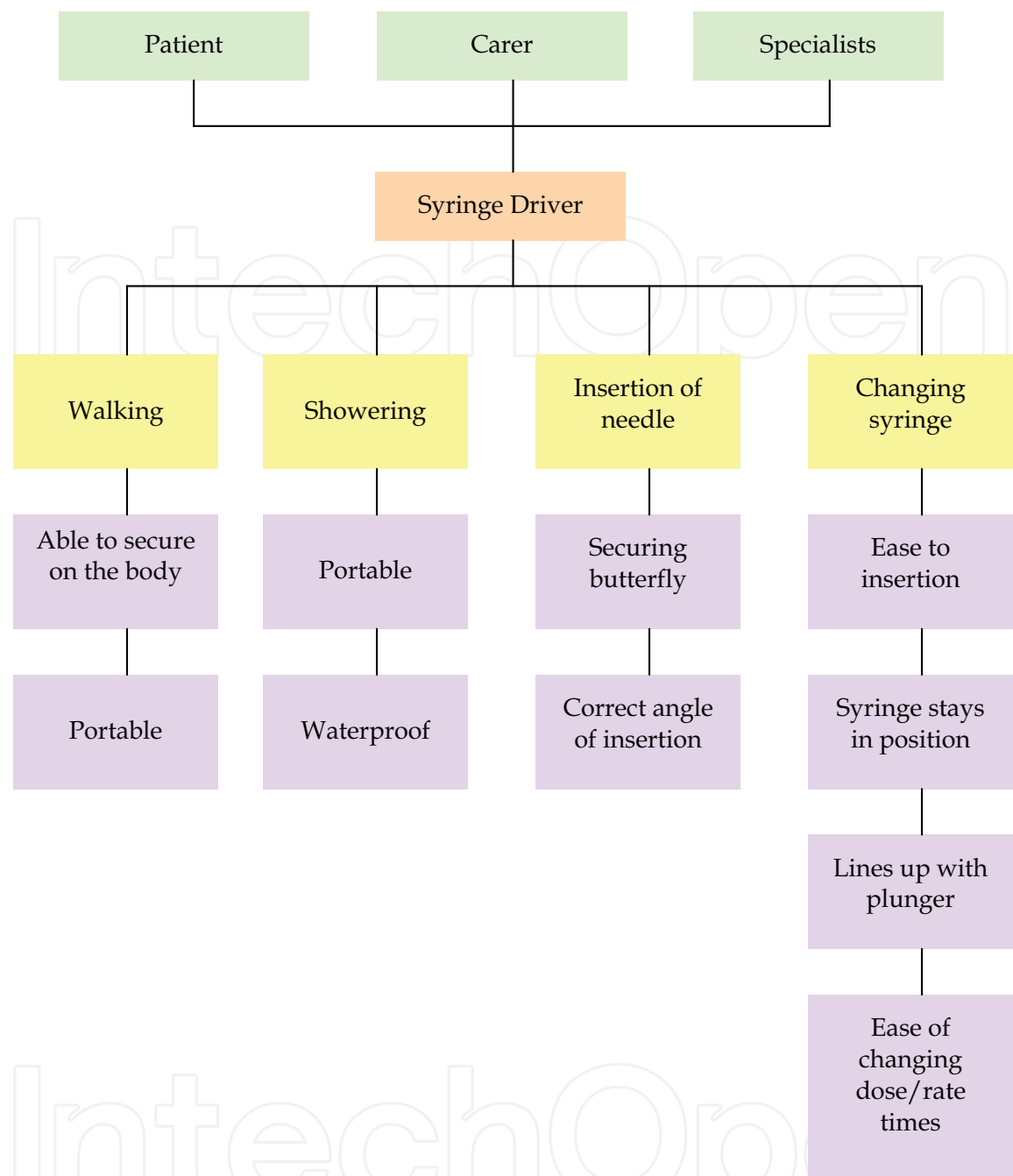


Fig. 3. *Object to User* Product Analysis Approach.

The flowchart maps the relationship between the intended user and the object. As the user engages with the product through daily rituals, the design process is informed about desired or required functions, form, bodily interactions and processes. The designer may then create a checklist or formulate a design hierarchy for evaluation. For example, a designer observed a carer changing the syringe. During the observation, the designer noticed that the carer was having difficulty keeping the syringe in place once secured back into the driver. The designer was drawn to the functional problem that the nurse was experiencing at the time. The nurse’s comment on the situation was “I know that when I walk away, the patient will pick the driver up and the end of the syringe will no longer be

sitting in the ridge. Maybe I'll put a piece of sticky tape over the top." This observation prompted the designer to make note of form and placement of syringe and may lead to innovative forms, material choices and mechanisms that would influence experiences.

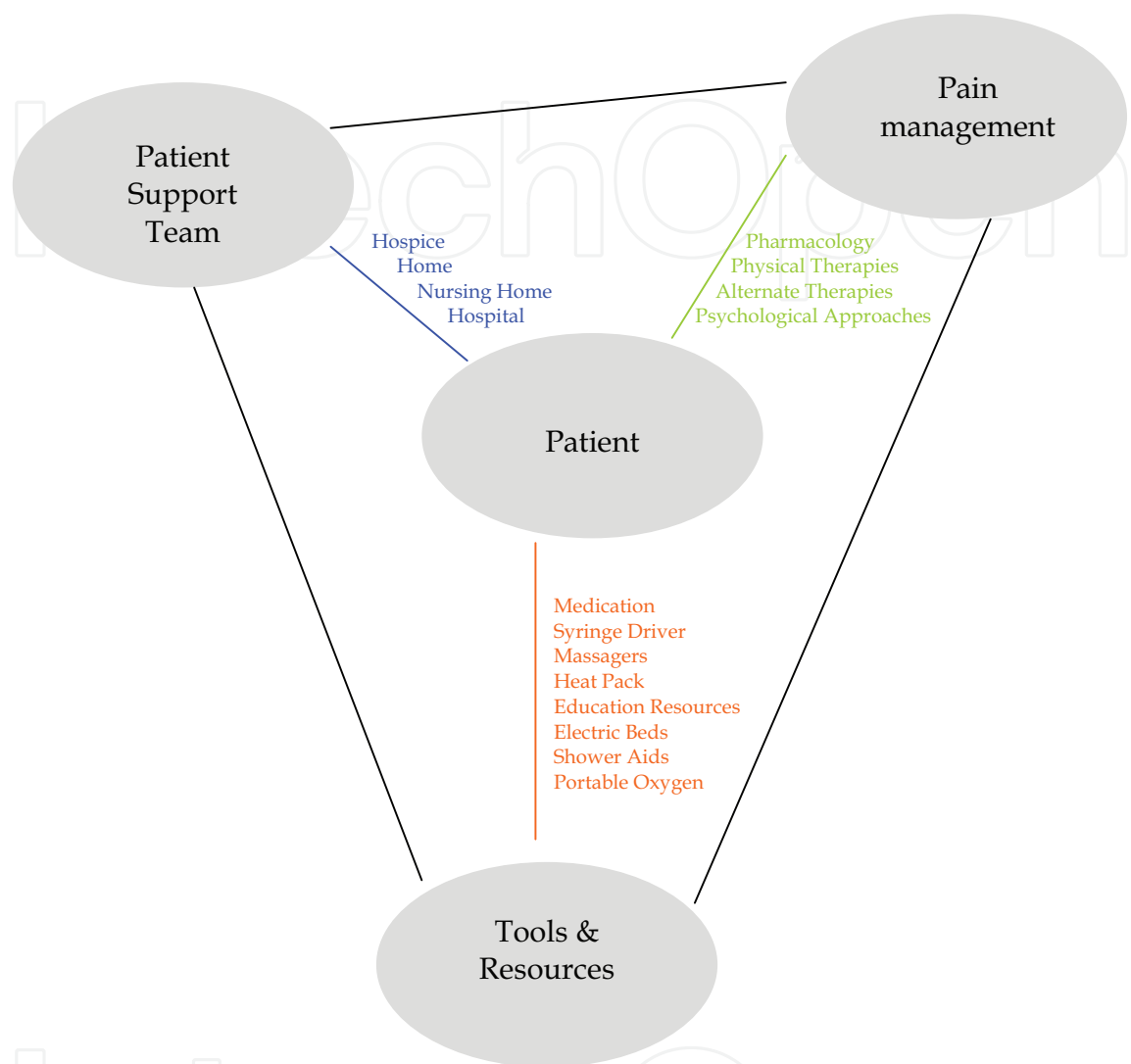


Fig. 4. Patient Centred Care Approach.

Through alteration of the model to reflect a patient centred care philosophy, the dynamic between the palliative frameworks will offer a holistic and broadened experience. In this model, the framework is turned towards the service offered and provided by the support team, pain management and the tools and resources. Pathways of exploration become clear as interactions and experiences become apparent. The syringe driver falls within the relationship between the patient and tools and resources but may also be expanded as experiences between the syringe driver and other factors crystallises.

In figure 5, examples of relationships between the syringe driver and the support framework have been identified. It through the relationships that experience can be evaluated and determined. The experience of use of the syringe driver may be very different in the home where the carer may be emotionally exhausted, stressed and anxious in

comparison to a hospice where there are several trained carers available. The expansion of design possibility may also be questioned. New relationships between the syringe driver and physical therapies may challenge designers to reconsider the purpose and intent of such a device. Materiality and form may offer a new form of therapy, for example textures that reflect different levels of pain or form that can be squeezed and moulded as pain increases. This process of questioning and reflection aims to redirect understanding and open the area of investigation. Variation of experience can be identified within such a model and drawn upon by designers to map points of direction and research.

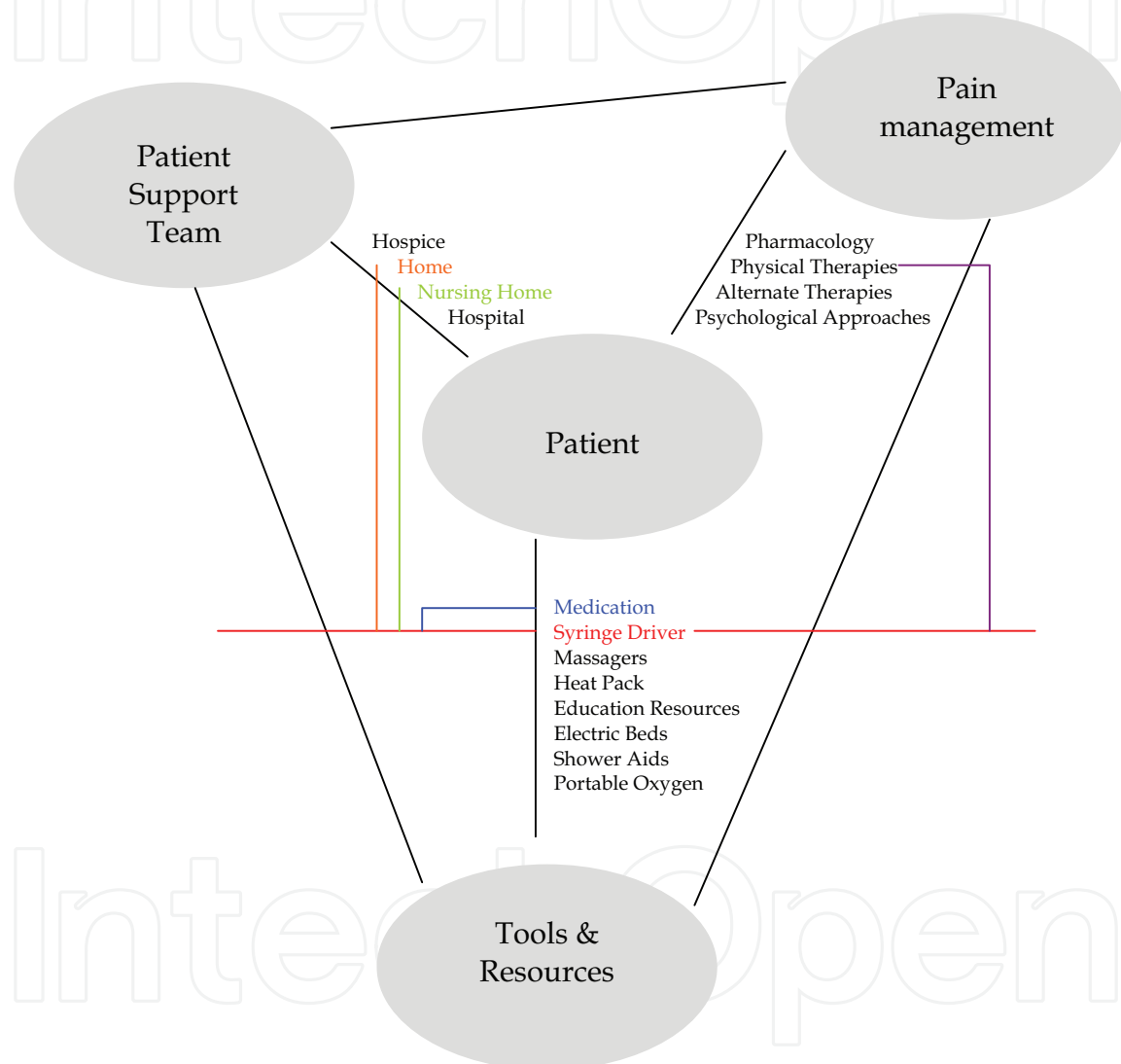


Fig. 5. Relationships formed1 with a palliative framework.

The frameworks illustrated reposition the palliative environment towards a service centred provider. Through mapping relationships, new research possibilities become evident. This process is primarily object centred and explores relationships and needs that pre-exist. Touch points within an experience may redefine the elements that contribute to the current syringe driver design and identify new points of exploration through narratives and feedback.

Through a flow chart of touch points the designer is able to reconstruct the experience prior to syringe driver use, identify the patients understanding of pain management and reconsider the positioning of the syringe driver within the experience. The flowchart shown in Figure 6 illustrates the touch points that may be encountered from the initial phone call to the palliative team to the first home visit by the community nurse. Alongside each touch points are concerns, questions or points of interest that the patient or carer may be experiencing during the process.

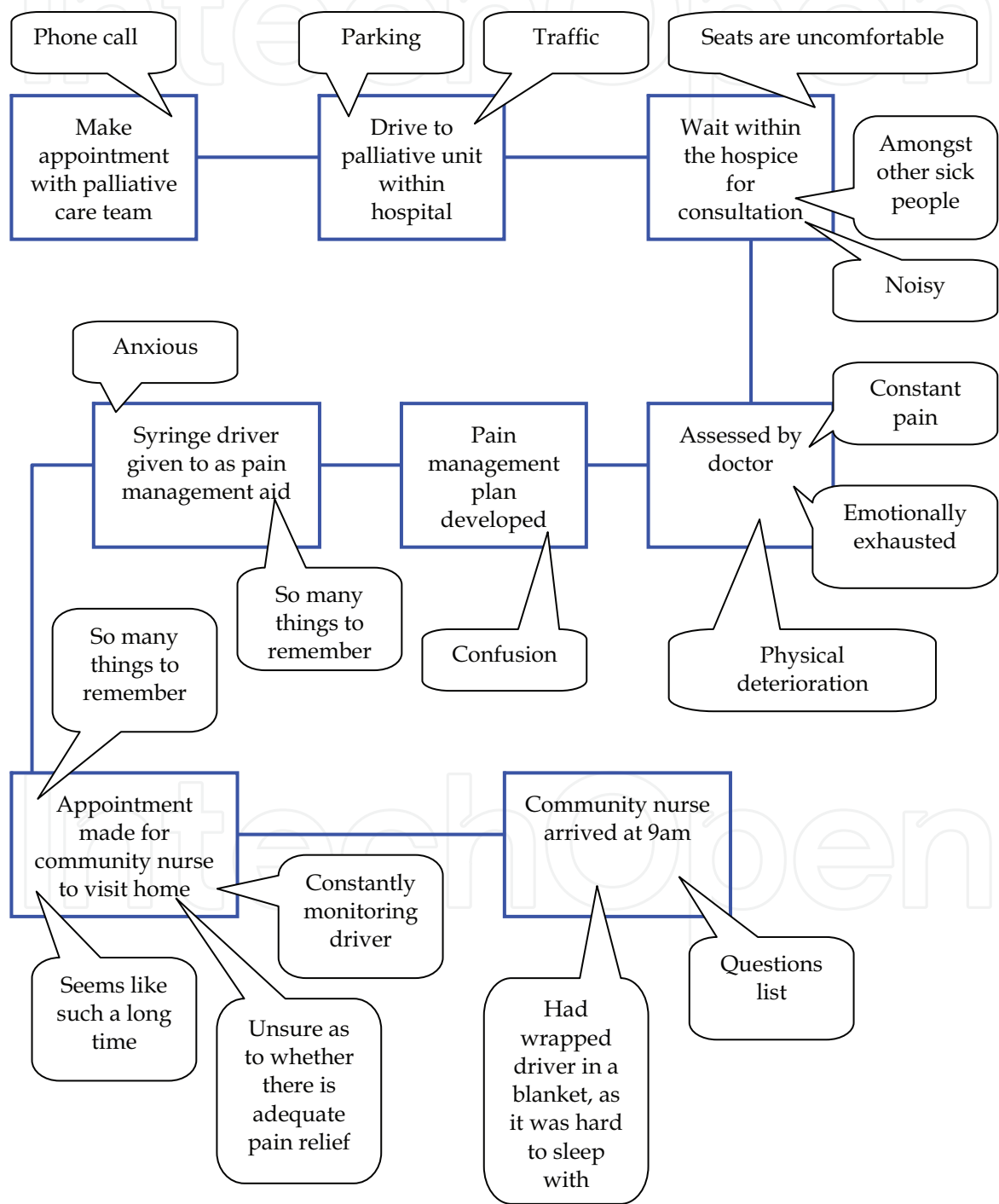


Fig. 6. Patient experiences map.

The patient experience map exposes elements that contribute to the patient's evaluation of the palliative service. The syringe driver that the patient engaged with may have posed difficulties and frustrations. When grouped with surrounding experiential factors such as the noise in the waiting room, uncomfortable chairs, being overwhelmed with information and suffering from severe pain, it may be evaluated that if design changes were made to the syringe driver to improve ease of use, the experiential analysis may still be poor. Through the map it becomes clear to the development team that the first of interaction, the phone call, is where the service to the patient begins.

As health services develop, integrated systems and technologies may aid in reducing poor touch points. The realm of digital health service aids, online training and support will help to reduce the pressure and stress placed on carers and patients. The design of products such as the syringe driver must reflect the way in which we interact with common service providers and the rising needs and expectations of the community. Whilst reflecting on the patient experience of a syringe driver, the development team may question the core ideals of the product, which is to provide consistent pain relief through pharmacology. By returning to the primary need, designers may begin to pose opportunities and new directions through questioning and evaluation. For example, is it necessary to use a syringe? Can we redesign the syringe to reduce the size? Can we design a syringe that is flexible? Can we design the whole device so that it is flexible?

4.3 Evaluation of experience and its role in shaping our understanding

The syringe driver case study demonstrated a strategy for the integration of experiential research within the design process. The experience of pain and its management is personal and unique to each individual. By drawing upon the experiences of others, the development team, particularly designers, is able to consider the complex needs of the patient. Through sketches, mind maps, touch points, photographs and videos the designer is able to respond in an interactive manner to the experiences presented. The ideal integration for experience is to provide a product to a patient that fulfils all the functions of a syringe driver but offers an emotional response. Future products should delight and surprise patients, they should be compassionate and understanding, trustworthy and honest. It is through innovative design concepts and strategies that products can endeavour to reflect human values.

4.4 Conclusion

The dynamic relationship between patient and carer is the centre of palliative care. It is a relationship that develops from a medical stem and matures into a connection based on emotions, spirituality, experiences and trust. Design is concerned with the development of physical forms and systems that acts as a response to the needs and experiences of this form of relationship. Design does not take the lead but rather acts as an aid. It aims to redefine the development process, to demonstrate to the environment the possibilities and opportunities and if executed correctly, design should be deeply embedded in the experiences of the patient.

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This book is designed to provide a comprehensive insight unto the key and most prevalent contemporary issues associated with palliation. The reader will find viewpoints that are challenging and sometimes discerning, but at the same time motivating and thought-provoking in the care of persons requiring palliation. This book is divided into three sections. Section 1 examines contemporary practice; Section 2 looks at the challenges in practice; Section 3 discusses models of care. This book is an excellent resource for students, practising clinicians and academics. By reading the book, reflecting on the issues, challenges and opportunities ahead, we hope it will create within the reader a passion to take on, explore and further develop their palliative care practice.

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