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# Homecare user needs from the perspective of the patient and carers: a review

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**Abstract:** There is a global shift towards a blending of care delivery within formal and informal environments in direct response to economic and demographic pressures. Homecare is at the hub of this activity, enabling people to age in place and keeping families intact. However, our understanding of patient and carer needs is fragmented; understandably so, given the complexity of these needs. This descriptive review offers a content analysis of papers focused on patients' and carers' needs and homecare published between January 2010 and October 2013. It is evident that homecare is an intensely researched area, yet it is disjointed. Emerging research emphasizes the need to take a holistic approach. Firstly, incorporating emotional psychosocial and cultural elements will help to draw together our current understanding within a more cohesive framework. Secondly, tensions that hinder communication and collaboration between stakeholders must be resolved. Thirdly, information and communications technology is rapidly becoming synonymous with homecare, and offers solutions for facilitating care delivery, collaboration, and training of future professionals. The rate of international activity promises much for future research collaborations to compare, contrast, and identify best practices for the future of homecare as we endeavor to meet the ever-increasing pressures on health and social care systems.

**Keywords:** homecare, home health care, patient needs, caregiver needs, telehealth, telemonitoring, patient-centered care

## Introduction

Within Western societies, there has been a shift from the delivery of health care in formal settings to a blending of health care delivery within both formal and informal settings.<sup>1-4</sup> To cope with the increasingly aging population, demands for hospital beds outstripping supply, and cuts in funding for hospital services, homecare is viewed as a viable solution to help reduce costs while maintaining quality of care.<sup>2</sup> The relative advantage of homecare in comparison to hospital care may not be clear-cut, relying heavily on the specific context and focused "capacity building" of the service.<sup>3</sup> However, advancements in technology and treatments support homecare as a feasible and effective option, raising the potential complexity of care provision possible at home to levels comparable with hospital care.<sup>5</sup> Most importantly, homecare is often the preferred option for many patients, their families, and carers, regardless of condition,<sup>6,7</sup> though the physical, monetary, and emotional costs of providing care at home can be a burden to patients and their families eventually.<sup>3</sup>

Homecare studies have tended to focus on one aspect of homecare – recipient characteristics and the organization of homecare – as revealed in a recent comprehensive review of homecare across Europe (January 1998 to October 2009).<sup>6</sup> To harness

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current knowledge more effectively and bring about better patient outcomes, a uniform framework and methodology for researching homecare are needed. A vital ingredient is that this framework be focused around an understanding of the patients' needs for homecare.<sup>6,8</sup> Therefore, the focus of this review is to establish how studies focus on the needs of patients and their carers in homecare. Three key questions are posed:

1. What does homecare mean to patients and their carers, and how does this help us to understand their needs?
2. What is the scope of studies to date that focus on the homecare needs of (a) patients, (b) carers, and (c) patients and caregivers together?
3. What is the scope of studies of homecare technology in relation to patient and carer needs?

Following a brief description of the review methodology, the paper is structured around answering these three questions. The scope of studies is evaluated through identifying the main themes within each category and summarizing the issues covered. As such, readers are provided with a comprehensive summary of the coverage of patient and carer needs in extant research. In conclusion, a framework for understanding patient and carer needs is offered alongside three recommendations for future research.

## Review methodology

As set out in the research questions, the goal of the review is to capture the scope of research to date, rather than offering a meta-analysis. A focused search was conducted using Medline of homecare studies conducted from January 2010 until October 2013. Entering the search terms "homecare" or "home health" and "needs" returned 714 papers. Each paper was visually inspected, and papers were excluded on the basis of being historical reviews; political statements; commentaries; events-based posters; finance- and insurance-related studies; legal studies; nursing home or hospice studies; evaluations of specific treatments where homecare was the context, not the focus; "homecare" of teeth that was not related to delivery of homecare to patients; pregnancy- and children-related studies; policy, system, and management overviews; mental health patient studies; occupational studies; and propositional papers. The vital criterion in selection was to identify those papers that studied patients' or carers' needs within homecare. This resulted in 182 papers being selected for further analysis. Ten of these studies related to the meaning of homecare needs. The remaining studies focused on patient needs (83), carer needs (29), patient and caregiver needs (32), and telehealth and device use (28).

A content analysis identifying the emerging themes within each category and the number of studies within each theme is presented. The main issues arising within each of those themes are summarized.

## What does homecare mean to patients and their carers, and how does this help us to understand their needs?

What we understand by the term "homecare" is surprisingly varied.<sup>1</sup> However, homecare definitions are understandably dominated by a professional or policy perspective, where homecare is defined at an operational level, ie, the formal delivery of care at home by health care professionals or accredited homecare agencies, such as nursing care or physical therapy. However, operational concepts of "formal" homecare vary in terms of the extent of what constitutes homecare, and are based on (and limited by) the political and funding structures that support these services, eg, the nature of domiciliary care to be provided. A further complication in defining homecare is that it demands an integration of both social and health care services to bring about successful care outcomes. However, the diversity in funding and organizational infrastructures for the delivery of health and social care services within many countries has promoted a fragmentation of these services.<sup>9</sup>

In contrast, patient-led (or carer) definitions of care often do not focus on a specific description of the "operational" care provided, but on wider aspects of life, such as emotional needs, quality of life (QoL), and empowerment. This means that the potential heterogeneity of care needs is vast.<sup>10</sup> The extent of perceived needs is influenced by patient appraisals of disorders, especially the "controllability" or "surmountability" of the illness, and by their associated perceived and actual coping resources.<sup>11</sup> Illness is "destabilizing" for patients and their carers, impacting on control, dignity, and decision-making abilities, and it is often these elements that drive a patient's concept of what constitutes care needs.<sup>11,12</sup> Care from the patient's perspective often centers on a sense of "being looked after".<sup>12</sup> This encompasses: 1) perceived convenience, accessibility, availability, and promptness of resources or services; 2) information about the condition, treatments, and alternatives; 3) interactions with caregivers (eg, sensitivity, empathy, friendliness, and respect); and 4) the physical comfort or otherwise of received care. An initial categorization of the diverse and complex patient and carer homecare needs is presented in Table 1.

**Table 1** Patient and carer need categories related to condition or illness

Need category	Patient-related	Caregiver-related
Treatment-related	Medication (including adherence to regimen) Nursing care Prescribed treatments and procedures Dietary instructions Urination and bowel problems Physical therapy Individualization of care	Management of care needs Physical labor
Activities of daily living (ADL)	Personal care (bathing, toileting, dressing, transferring, eating) Instrumental ADL (shopping, light housework, meal preparation, money management, telephone access) Mobility (climbing stairs, getting outside the home, ability to walk) Fulfilling role commitments (care of others, work-related)	Physical burdens Restrictions on autonomy/independence Restrictions on leisure time Spillover to other areas of life
Self-sufficiency needs	Transportation Housing Legal Finance Work	Increased responsibility Financial needs or burdens Transportation needs or burdens
Social needs	Interpersonal interactions Social support (from those sharing the same home or from the wider network) Open discussion Avoiding dependency or “institutionalization in the home”	Help to adapt to disorder or death Strengthening of family ties Pressure on family and friend networks Open discussion Social reintegration (especially outside the inner network) Not encouraging dependency (not “killing with kindness”)
Emotional needs	Role change (eg, from parent to “child”) or identity (self-concept) needs Loss of independence Coping with physical restrictions (anger and depression) Fears of being alone Guilt Coping with added responsibility Respite Indebtedness Demoralization	Role change (eg, from child to “parent”), impact on marriage or partnerships (eg, loss of spouse) Burnout Distress Felt responsibility Emotional labor Nonreciprocity in nature of exchange relationship (being “taken for granted”) Guilt Respite Self-esteem Desensitization to condition Demoralization Inadequacy
Informational needs	Treatment uncertainty Outcome uncertainty (eg, longevity, changing needs, “realistic” expectations, “healthy” appraisals of condition) Condition myths	Treatment uncertainty Outcome uncertainty (eg, changing needs) Condition myths (eg, fears of contagious nature of disease) Appropriate care provision

The changing nature of needs necessitates ongoing management with constant appraisal of the needs–care match. However, “home” in a service-delivery context is complex. The great variety in homes means that there is no level of standardization, making it difficult to develop protocols for service delivery or to guarantee that all services can be delivered.<sup>2,13</sup> From the patient’s point of view, their home is linked to their personal identity, and is a sign of independence, status, and

family tradition, which offers security and privacy.<sup>2,14</sup> Home is an important “therapeutic landscape” for the individual. The sense of attachment, continuity, and normalcy associated with homecare encourages feelings of well-being and enhances the efficacy of homecare by offsetting destabilizing effects of illness.<sup>2,15</sup> The home is often the preferred choice of place to die, as it is easier to manage the taboo associated with death, dying, and serious illness,<sup>16</sup> although the patient

must perceive this care as appropriate, otherwise its value is reduced or even detrimental.<sup>15</sup> The home as the context of care results in a complex interweaving of interactions between formal and informal carers and patients that are different from formal service settings.<sup>15</sup>

Notwithstanding, there is general agreement between patients, professionals, and carers that the goal of homecare is to enable an individual to remain in their home safely while receiving the services necessary to care for their condition-related needs, either following hospitalization or to prevent admissions and to facilitate aging in place. Put simply:

“Homecare is the total of services of healthcare that a patient can receive in his house, [ . . . ] provision of nursing care of high quality under medical follow-up and at the same time the provision of social and psychological support of the patient and his family.”<sup>17</sup>

While this poses challenges for homecare researchers in terms of the diversity of needs that could be studied, making a uniform framework difficult to develop, it does emphasize the importance of incorporating a holistic perspective on homecare into our studies.

## What is the scope of studies to date that have focused on the homecare needs of patients?

As a means of understanding what a holistic perspective might encompass, a content analysis of the 83 studies focusing on patient needs was undertaken. Studies addressed a diverse range of patient needs, from issues related to access through to needs associated with specific conditions. The emerging themes are presented here, and the key issues raised under each theme are summarized.

### Access to care (six studies)

Homecare can widen and promote equality in access to care.<sup>18</sup> The reality of receiving treatment is that it places temporal, financial, and transportation burdens on the patient and/or carer, and for younger patients the need to arrange time off work.<sup>7</sup> Homecare relieves these burdens for those living in rural and remote areas or those in vulnerable groups, such as poorer communities, the elderly, those with lower education, and those with reduced functional abilities.<sup>7,18–20</sup> Those living in urban areas were more likely to live alone and have less access to informal caregiving (51.2% in urban areas versus 82.8% in rural areas).<sup>19</sup> However, those in rural communities may be forced to rely on informal care because of lack of access to formal services.<sup>21</sup> Municipal characteristics impact on the

amount and type of care an elderly person receives, even when they share similar care needs and personal characteristics.<sup>22</sup>

### Need profiles (six studies)

Many of the studies reviewed focused on one or two specific aspects of homecare needs.<sup>6</sup> Three studies focused on a wider profile of needs, confirming the complex mix of needs that patients (and their carers) have, ranging from medical and physical to the psychosocial.<sup>23–25</sup> These studies identified malnutrition (57%), weakness (41.3%), and functional impairments (40%) as the most prevalent needs across a variety of disorders. A comparative study identified heart failure patients as having an overall more complex need profile than other conditions.<sup>26</sup> Two population studies estimated that the need for homecare in cancer patients may be as high as 69%–75.4%.<sup>27,28</sup> Robison et al draw attention to unmet psychosocial needs, which must not be overlooked.<sup>25</sup>

### Unmet needs (15 studies)

Studies estimate that between 23% and 50% of homecare patients have unmet needs.<sup>29,30</sup> Unmet needs cover all areas, including activities of daily living (especially fall management), mental health, accompanying acute health problems, family caregiver burden, transportation, housing, and general practitioner lack of knowledge.<sup>25,29–31</sup> Concerns are raised about the resultant impact, such as increased nursing home admissions (eg, patients are 1.8 more times likely to be admitted when they have unmet needs).<sup>29</sup> A lack of recognition of self-harm ideation and untreated depression leads to increased morbidity and mortality, increased nursing home institutionalization, and increased caregiver distress.<sup>32,33</sup> Critics highlight that many avoidable risks are not given high priority, eg, fall prevention, oral care, and foot care.<sup>34–38</sup> Homecare programs can create unintended harm for patients, eg, mismanagement of nutrition, pressure ulcers, and medication regimens.<sup>39–41</sup> Elder abuse recognition rates were low among professionals, suggesting mandatory abuse training for professionals and strategies to support reporters of suspected abuse.<sup>42</sup>

### Treatment-related needs (eleven studies)

Studies concerned with treatment-related needs focused on malnutrition and anorexia (five), medication (four), pressure-ulcer prevention (three, two of which linked malnutrition with pressure-ulcer incidence), and pain management (two). The risk of malnutrition was viewed as a significant need.<sup>39,43,44</sup> Incidence rates were similar across the two studies that quoted these, estimating malnutrition at 12% and 14% and high risk of malnutrition at 46% and 57%.<sup>23,43</sup> The incidence

of anorexia was 25%.<sup>45</sup> Those with higher dependency (eg, lower functional ability) or in specific disease categories (eg, cancer) may be at a higher risk of malnutrition.<sup>23,43,44</sup> Crucially, anorexia was linked to higher rates of mortality.<sup>45</sup> Malnutrition was closely linked with the development of pressure sores.<sup>39,43,46</sup> The estimated incidence of pressure ulcers in a homecare population was estimated at 14.3%.<sup>46</sup> Close supervision by the primary caregiver and education are primary factors in reducing pressure ulcers.<sup>39,46</sup>

Patients with complex medication regimens require support to avoid hospitalization.<sup>40</sup> The incidence of medication-related problems in the homecare population may be around 4.6%.<sup>47</sup> However, this figure may be considerably higher for patients with eight or more medications – around 61%.<sup>48</sup> Problems are linked to medications not suitable for debulking into weekly dispensing systems, being interrupted when preparing medications at home, changes in medications not being communicated, suboptimal therapy, and use of unnecessary drugs.<sup>40,47</sup> Of the three studies focusing on pain management, two established the safety and efficacy of patient-controlled analgesia in the homecare setting.<sup>49,50</sup> The other study estimated that 1.4% of homecare patients in significant pain may have thoughts of suicide, with pain being linked to self-injury ideation in men.<sup>33</sup>

### Activities of daily living (eleven studies)

The studies focusing on incidence of adverse events (two) reported remarkably similar rates of 13% per 100 patients and 13.2% across a mix of conditions.<sup>41,51</sup> The two largest categories of adverse events are those related to medication (described earlier) and to falls. It was estimated that over 50% of these adverse events could be preventable.<sup>41</sup> Reported falls incidence ranged from 55.7% to 70.6% of patients having at least one fall, 27.5%–44.2% of patients having recurrent falls across a mix of disorders.<sup>34,52</sup> Falls were linked to malnourishment, specific disorders (cardiovascular diseases, hypertension, diabetes mellitus), pain, reduced vision, reduced cognitive ability, and environmental hazards.<sup>34,35,53</sup> Emphasizing the lack of control over the home environment, one study revealed that 91% of homes have hazards related to falling, a rate of 3.3 per patient, with each hazard increasing the risk of a fall by 19%.<sup>53</sup> As the risk of falling changes over time for each patient, it is difficult to assess for individuals.<sup>53</sup>

In relation to personal care, oral health and foot problems were neglected areas of homecare needs.<sup>36,37</sup> The status of oral health was linked with nutrition through its impact on denture wearing and swallowing function, those with natural teeth having the fewest problems.<sup>38</sup> Patients suffered from

multiple foot problems, including edema, and thickened and discolored toenails, yet found it difficult to look after their own feet.<sup>37</sup> In relation to functional ability, in a population study including Europe and Canada, there were wide differences in incidences of visual decline, ranging from 6% to 49%.<sup>54</sup> Visual decline is associated with reduced social contact, especially in outdoor activities.<sup>54</sup> Homecare patients are in general weaker than normal for their age and sex, with 85.4% experiencing weakness in hand grip on one side or other.<sup>55</sup>

### Social and emotional needs (eleven studies)

Depression, anxiety, and associated insomnia were significant problems for patients in homecare.<sup>56–58</sup> Emotional dysfunction is the least well-identified and least well-treated need in homecare patients.<sup>25,56</sup> One study estimated that 12% of patients in homecare suffer from depression, yet less than half of these receive appropriate treatment.<sup>57</sup> Those that do receive treatment for one of these conditions may suffer side effects from long-term use of drugs.<sup>58</sup> The importance of contact with the caregiver as a means of meeting comfort needs, the need to be connected, and alleviating loneliness cannot be underestimated in these cases.<sup>59,60</sup> Homecare patients have the need to feel safe in their homes, receive empathy, and receive encouragement for participation in their health care.<sup>61,62</sup> Those patients with end-of-life needs may have very specific wishes, eg, the wish to die at home or spiritual needs, yet they need to feel that their wishes are being listened to.<sup>63,64</sup> There is a need for space for open discussion about “taboo” subjects, such as dying, but also communication with others that allows them to involve those around them in their “journey” and to take responsibility for the future.<sup>65</sup>

### Informational needs (two studies)

Four key informational need areas were identified as important and neglected: 1) medication, specifically regimens, 2) disease or condition, specifically severity, 3) nonmedication, specifically hospital-discharge processes, wound care, medical equipment use, home safety, and extent of care, and 4) functional limitations.<sup>66</sup> Communication problems were identified, in particular the need for continuous and updated information during treatment and care regarding prognosis and longevity of care.<sup>61</sup>

### Empowerment, quality of life, and homecare programs (26 studies)

Homecare is a route to empowering patients.<sup>61</sup> It can increase the acceptability of treatment and enable the choice to stay

at home.<sup>7</sup> For example, in one study, homecare enabled fulfillment of 98% of patients' choice of place of death.<sup>67</sup> Participation in care is more achievable than in a hospital setting; patients are able to cocreate their care with homecare workers and have a choice over who works in their home.<sup>62</sup> Many patients seek to "get on with life", constituting performance of daily activities, managing health, integrating life, and getting out/participating in life, with the best QoL that they can have.<sup>13,68</sup> Homecare facilitates QoL by enabling people to stay in contact with their lives and families.<sup>7,69</sup> Homecare programs can increase QoL, yet homecare can often be disrupted by funding shortages.<sup>68,70</sup>

Adopting such approaches as patient-centered homecare that focuses on the emotional and psychosocial aspects of disease, health-promotion activities, and restorative homecare programs facilitates QoL by increasing independence and empowerment.<sup>67,71-80</sup> One study compared the Aging in Place (AIP) program with nursing care in the home, and found AIP to be an efficient and less costly service.<sup>81</sup> While depression and anxiety linked with physical symptoms, especially pain, impact on QoL, these can be alleviated through appropriate emotional support, such as someone who will empathetically listen to anxieties and experiences.<sup>82,83</sup> Through "accommodation", care provision can be responsive to the "singularity" of older adults to truly support independent living.<sup>84</sup> Delivery of therapies within the homecare setting can alleviate impacts on QoL traditionally associated with hospital settings. For example, an intensive chemotherapy regimen at home was found to be feasible, effective, and not to reduce QoL for the patient.<sup>85</sup>

### Patient satisfaction (12 studies)

Patient satisfaction with homecare is considered an essential means of benchmarking, identifying best practice, and delivering quality care.<sup>86</sup> Homecare can improve patient satisfaction with health care.<sup>5,87</sup> Assistive devices in homecare settings are most often associated with increased satisfaction with care.<sup>88-90</sup> However, a lack of consensus over the constituents of satisfaction and its measurement have hindered its use in the monitoring of homecare.<sup>86,90</sup> Patient satisfaction can be summarized in four key dimensions: availability, accessibility (nondiscriminatory, physical accessibility, affordability, information accessibility), acceptability (eg, adequate conditions at home, not being afraid to use assistive devices or follow medication regimens), and quality.<sup>91-96</sup> Some have emphasized the advantages of a qualitative approach to "connect the voice" of patients, caregivers, and professionals, although the level of commitment required for such an approach is huge.<sup>92</sup>

### Reducing hospitalizations, mortality, and costs (eleven studies)

Homecare reduces hospitalization, readmission rates, use of emergency services, and associated costs.<sup>5,67,69</sup> For example, a US-based comparative trial of the AIP program versus nursing homecare showed reduced costs of \$1,591.61 per month in the AIP group.<sup>81</sup> Homecare reduces avoidable hospitalizations in particular, especially in remote areas.<sup>20</sup> Reasons for this include patients not being exposed to nosocomial risks, higher "attendance" rates than clinics, and alleviating the risks of seeking care too late.<sup>7,19,69</sup> There is evidence of reduced mortality risk in those patients receiving homecare, especially in vulnerable groups.<sup>97,98</sup> Cost savings are found through the optimization of specialist nursing time.<sup>7</sup> However, homecare needs to be targeted at the right patient population; it is not a blanket remedy. Costs are uniformly reduced in homecare settings, and the use of homecare and costs increase each week before death.<sup>99,100</sup>

### What is the scope of studies to date that have focused on the homecare needs of carers?

Of these studies, 18 focused on formal (paid) caregivers, and only eleven on informal caregivers. As earlier, the emerging themes are presented, and the key issues raised under each theme are summarized. With regard to the informal caregiver category first, these studies overwhelmingly focused on their emotional or social needs. Only one study focused on the information needs related to the care of hemodialysis patients.<sup>101</sup>

### Emotional and social needs of informal caregivers (ten studies)

The Family Difficulty Scale identifies eight categories of concerns: burden of care, concerns about homecare doctor, balance of work and care, patient's pain and condition, concerns about visiting nurse, concerns about homecare service, relationship between family caregivers and their families, and funeral preparations.<sup>102</sup> One study found 22% of informal caregivers could be formally classified as distressed.<sup>103</sup> Distress was a function of the interaction between the severity of the patient's condition and functionality, and the degree of the carer's positive outlook and personal resources.<sup>103,104</sup> Uncertainty with regard to outlook and continuity of financial burdens exacerbated caregiver distress.<sup>105</sup> The burden related to ongoing surveillance in terms of provision of care, prevention of injuries, and home safety was noted.<sup>106</sup>

The relationship between family caregivers and formal home-health professionals is important, especially in situations where the patient is unaware of the severity of their condition.<sup>107–110</sup> The focus of this relationship is often on a negotiation of caregiving, helplessness, and interventions.<sup>108</sup> A good caregiver–nurse relationship results in practical benefits, such as assisting in assessment of needs and improving access to necessary care,<sup>110</sup> whereas a poor relationship leaves caregivers with feelings of powerlessness and “being left out”; they have a need to be “visible” in the care process.<sup>109</sup> Caregiver and nurse perspectives could be misaligned, as caregivers are focused on the particular care of a single patient, whereas nurses are focused on shaping different realities within different homes.<sup>107</sup>

Two studies focused on the social norms or pressures to take on the role of caregiving. Caregivers often take on the responsibility of caring as a “natural” role.<sup>109</sup> However, it was noted that female caregivers may take on the role of caregiver to a spouse because of the “gendered standards” with regard to caregiving roles in society. In such cases, other duties or roles may be neglected and women’s choices reduced.<sup>111</sup>

## Formal caregivers (18 studies)

### Job strain and changing environment (seven studies)

While occupational studies are not within the scope of this review, seven studies that focused on the overall strain of the job are pertinent here. Four studies highlighted the responsibility, safety, and physical demands of the role, in accordance with Table 1.<sup>31,62,112,113</sup> These studies highlighted training gaps and the need for direction from supervision and appropriate documentation and guidelines.<sup>31,62</sup> The other three studies focused on the fast-changing environment and its impact on formal caregiving. Fragmentation of care, characterized by increasing time pressures, pressures on care resources, and increased demand, was experienced by care workers as “being on the verge”,<sup>114–116</sup> ie, increasingly feeling that they are being pushed to the limits of their capabilities and increasingly working against their professional standards, with concerns for the delivery of quality care.

### Treatment-related (five studies)

It was estimated that 80% of formal caregivers provided nursing care in the home (50% moderate-to-complex tasks), which was experienced as significantly more straining than the provision of personal care.<sup>117</sup> Four studies focused on exposure risk (blood and body fluids). Top risks were from dressings (31.1%), capillary blood glucose monitoring (14.4%), and vascular access (3.1%), deemed to be at a

risk level comparable to the hospital environment.<sup>118</sup> In one study, 6.3% of homecare workers reported an incident of exposure to blood or body fluids.<sup>119</sup> Only 86% of homecare workers in one study reported always being provided with the correct protective equipment; adverse working conditions impacted on its use.<sup>120</sup> Lack of an infection-control management plan and increased risk in smaller homecare agencies was noted.<sup>121</sup>

### Emotional and social needs (six studies)

The role of the professional caregiver is multifaceted, incorporating acceptance, listening, support, and direction within a genuine caring dimension.<sup>122,123</sup> Within the sociocultural context of care, homecare workers face contradictions or tensions concerning these elements. They need to connect with the patient and/or families and be able to withdraw, they need to enable patients and families, and at the same time administer care or make decisions that are disabling.<sup>114,124</sup> They need to be able to visualize and communicate with patients and families about what is to come and what can be done.<sup>125</sup> In terms of decision making, they need to take account of family caregivers, the patient, and the context of care.<sup>110</sup>

### Informational needs (one study)

One study evaluated homecare workers’ knowledge of evidence-based education topics in managing heart failure.<sup>126</sup> While there was a 78.9% knowledge level in heart-failure education principles, some areas were weak. These included knowledge related to asymptomatic hypotension (24.5% correct), daily weight monitoring (26.6% correct), and transient dizziness (30.9% correct).

## What is the scope of studies focusing on combined patient and caregiver needs?

Thirty-two studies focused on the interrelationships between patient, family, and professionals. When the home becomes a place of care, the meaning of this formerly private area is changed, and the meaning of professional care is also changed.<sup>127</sup> Homecare, as a cocreating activity recognizing the authority and influence of the person in their own home, can be delivered through “friendships” rather than “power relations”.<sup>127</sup> Cocreation is a prerequisite for the negotiation of intimate care.<sup>15</sup> The cooperation of the entire family in care is associated with greater family health.<sup>10</sup> When an informal caregiver is present, nonadherence is reduced; conversely, caregiver strain is associated with increased non-adherence.<sup>26</sup> Caregiver confidence about the patient’s ability



to recover leads to improvements in activities of daily living; when both parties are confident, even greater improvements are observed.<sup>128,129</sup>

Stakeholder communication and collaboration were major concerns.<sup>5,66,130</sup> Homecare relies on information sharing across multiple stakeholders, yet there is a lack of consensus on how this should be done.<sup>131</sup> Transparent and flexible communication and collaboration between patients and their families and professionals is required.<sup>132–134</sup> Interventions to improve communication and collaboration include professional training, partnerships with pharmacists, and community activities.<sup>135,136</sup> New care models foster successful collaborations, eg, specialist schemes for palliative care at home and the implementation of shared decision making in homecare.<sup>137</sup> Collaboration studies evaluated interprofessional teams and shared-care models for overall care, transition to homecare, fall prevention, formal and informal caregiver communication, and cooperation between device manufacturers and health care teams.<sup>138–143</sup> In terms of identification/evaluation as a means of improving care, two studies focused on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses and Omaha Systems.<sup>144,145</sup> Specific tools evaluated included the Resident Assessment Instrument – Homecare.<sup>146–150</sup> Other tools evaluated were the Support Needs Assessment, the Five-Repetition Sit-to-Stand Test, the Care Dependency Scale, and the Palliative Prognostic Index.<sup>146,151–153</sup>

## What is the scope of technology and the future direction of homecare delivery?

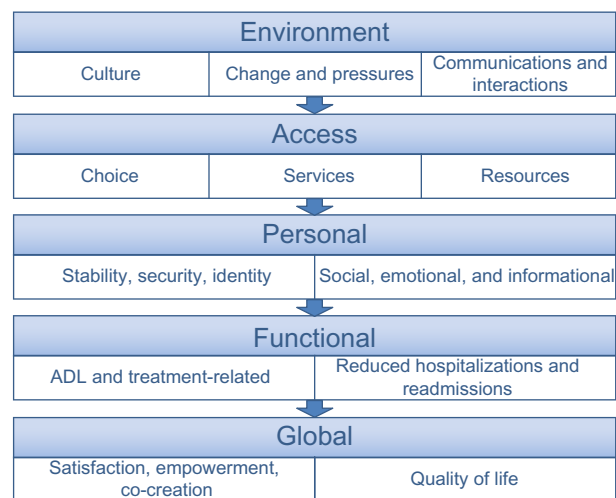
Information and communications technology (ICT) is making significant strides toward improving the delivery of homecare. It is difficult to envisage the future of homecare without ICT playing a significant role. There are a variety of ICT tools that can increase accessibility to homecare and enable people to gain control of their illness and promote self-management.<sup>154</sup> However, surprisingly few studies (28) focused specifically on telehealth, telemonitoring, and other technological interventions within the context of patient and carer needs. There were of course many more studies on the technical development and implementation of such tools, but they are beyond the scope of this study.

Four of these studies detailed successful outcomes of trialing telehealth support for medication and related symptoms, including a shared electronic care plan for professionals.<sup>35,155–158</sup> Seven studies reported successful outcomes of telemonitoring.<sup>106,159–164</sup> Mobile computing devices

for information sharing, decision making, communication, and developing social capital were developed.<sup>165–171</sup> Technologically supported systems for self-management and home-therapy techniques were also reported.<sup>171,172</sup> Practitioner caution on the use of mobile technology was explored, and the need for educational resources and user-centered design in implementing technological solutions was identified.<sup>146,173</sup> The important role that assistive devices play for homecare staff (time and cooperation) and patients (coping and emotion) was assessed.<sup>174</sup> Devices reported on were a self-administrative device for subcutaneous immunoglobulin therapy, continuous drug delivery through an infusion set versus pump, a mobile ultrasound device, and a lightweight hospital bed for use in the home (easy to assemble and transport).<sup>69,175,176</sup>

Usability and cost models for medication dispensers and safety in homecare were assessed.<sup>88,177</sup> The development of mobile clinical pathology laboratories for homecare was looked at, where equivalence of mobile and clinical laboratory measurements was achieved.<sup>178</sup> These add value by assuring provision of laboratory results for homecare patients in minutes, allowing real-time modifications in therapy and reducing the number of second visits by a homecare team. While mobile laboratory tests were more expensive, this was offset against savings in patient hospitalization and reduced second visits.

Simulations offer promising solutions for improved training to enable professionals to manage the complex homecare environment. For example, a human patient simulation has recently been developed for education of homecare nurses. The program enables studies to increase nurses' confidence in dealing with the homecare environment.<sup>179</sup> A similar



**Figure 1** A framework to understand stakeholder homecare needs. **Abbreviation:** ADL, activities of daily living.

simulation technology was used for teaching medication management for homecare nurses, with a significant increase in nurse self-confidence and improved knowledge of medication management.<sup>180</sup> A particular advantage of this approach was that students made mistakes in the simulations, which they may have made in the real setting. Others are exploring the use of virtual reality for homecare training, eg, the Living Environments Lab (Wisconsin Institute for Discovery, Madison, WI, USA), a fully-immersive six-sided virtual reality computer-assisted virtual environment to enable recreation of household environments.<sup>181</sup>

## Conclusion

The future of homecare is promising, with exciting developments in technology to help us optimize systems, realize the full benefits of care, identify best practices, and help us to meet the oncoming challenges of an ever-aging population in place. The home as a therapeutic setting enables elders to age in place and facilitates patient empowerment, self-care, and QoL. It is envisaged that self-management of health will become more of the norm than the exception in the future, complicated and driven by the aging population.<sup>13</sup> In this regard, homecare can be an efficient mode of service delivery, although this is by no means conclusive.

The scope of the studies on homecare needs reviewed here is vast and varied. Research is understandably fragmented, both by topic (many studies adopt a narrow focus) and geographically (there is a paucity of comparative studies by country or culture). Despite calls for more integrated studies,<sup>6</sup> these are still lacking. Given that the needs of patients and both formal and informal carers are complex, to take our understanding of needs forward will require building on the emerging stream of research conceptualizing the home as a caring environment. While it is challenging to answer calls for a uniform framework of patient and carer needs to advance homecare research, it is also necessary. Figure 1 presents a framework that draws together the needs identified within this review.

Patient and caregiver (formal and informal) needs can be categorized at multiple, interdependent levels. We can locate studies within this matrix to understand their meaning within the broader categories of needs. More importantly, we can use such a framework to guide a more holistic approach both to incorporate multiple needs categories within our studies and to illustrate how significant technological developments apply to and fulfill these needs. The latter point is strongly indicated by the lack of studies that transparently link needs and technology.

Finally, three key areas are identified to drive future research agendas. Firstly, the cultural context and social drivers of care-seeking and care-giving behaviors need to be understood in terms of how these differentially impact on care provision and acceptance.<sup>74</sup> Within this, the ethical implications of the shift from institutional care to technology-assisted homecare and the subsequent impact on the care recipient and formal and informal care providers should be evaluated.<sup>15</sup> On one level, we could explore in more depth the differences between rural and remote communities in terms of cultural and support networks and the impact on care provision. On another level, we should encourage more international comparative studies to help to understand the contrasting impact of diverse cultures and environments (eg, Japan, Scandinavia, and the US).

Secondly, homecare takes place in a complex environment, with multiple stakeholders. The need for information sharing and collaboration between stakeholders is essential to optimize outcomes for patients, their families, and professionals. However, this is the area of most controversy and concern; we do not yet know how best to achieve stakeholder collaboration. Increasingly, studies are focusing on the development of new care models that can foster successful collaborations. A future research agenda that focuses on the use of informatics for information sharing is indicated.<sup>21</sup> An unusual program to educate a local community on the use of opioids with the goal of building capital in the community for future care is noteworthy.<sup>182</sup>

Thirdly, it is clear that technology has a crucial role to play in enabling us to optimize the advantages of homecare: 1) technology changes the nature of homes in the future, eg, assistive and monitoring devices, 2) brings formal services closer to the home, eg, mobile laboratories, 3) serves a vital function in communication, eg, multistakeholder collaboration, and 4) greatly expands the scope of training, eg, simulated environments. As part of a plan of integrated studies, technology must be developed and assessed in relation to specific stakeholder needs rather than as part of fragmented pilot projects.

## Disclosure

The author reports no conflicts of interest in this work.

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